BREAST CANCER:

Women's Experiences of Decision-Making and the Role of the Nurse Counsellor

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Dedicated to all my family with love, and above all to my parents who have given me endless support throughout it all!

מוקדש למשפחתי באהבה -
אביבית, עמרי, שחר, טל ושקד
גוני, דורותיאה, שירן ולירון
ובמיוחד להורי שושנה ונפתלי
שנתנו לי תמיכה ללא גבול לאורך כל הדרך!

DECLARATION

I declare that the material in this thesis has been written by myself only, unless otherwise mentioned.

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ABSTRACT

This thesis is concerned with women making decisions about their treatment in the situation of primary breast cancer. How do women experience the decision-making? What is the value of nurse counselling of women at that stage? In order to answer these questions, participation in the choice of treatment for primary breast cancer is explored, from the point of views of both the women and the nurse counsellors. The argument behind this work is that only through listening and understanding the women can nurses provide appropriate counselling and support. An insight into how the nurse counsellors perceive the women's experiences of decision-making and their own supportive role, adds another informative dimension to the topic under study.

Four main areas are discussed in the review of the literature: the medical treatment of primary breast cancer, the psychosocial aspects of breast cancer, the women's participation in the choice of treatment, and nursing intervention and counselling in the decision-making process.

The research method used is based on the phenomenological line of thought, involving an in-depth exploration of thoughts and views of women with breast cancer who have faced decisions regarding their treatment. Ten women were individually interviewed, and later a group meeting of all these women was held for further discussion. Another group discussion with twelve women attending a 'Reach for Recovery' self-help meeting took place. In addition, seven nurses working as counsellors in breast cancer care were separately interviewed.

Twelve themes emerged during the analysis of the data relating to the decision-making experience. These themes suggested a social process of decision-making which was experienced by the women. Three different social realities: the **self-world**, the **relationship with the doctor**, and the **network of support** are discussed in relation to decision-making. The doctor was seen as 'invading' the Self-World, and the Network of Support provided the means by which the women regain the stability of the Self-World. In relation to nurse counselling as a specific form of support, six themes were analysed: the **timing** of counselling, counselling as a source of **information and advice**, the **emotional support** given by the specialist breast-care-nurse-counsellor, the **holistic** approach to counselling, the **training** of the counsellor, and finally, the **limitations** of nurse counselling.

A description of the women's and nurses' perceptions of each of these issues is given. The researcher herself and her experiences form an integral part of the research process. Based on the analysis of the data, practical matters related to breast care nurse counselling are addressed.

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Chapter I:

INTRODUCTION

מחוץ לגוף

הַמְהַפְנֶטֶת הָיְתָה אֶצְלִי
דִּבְּרָה עַל הַגּוּף הֶעָיֵף מִכָּל הַשָּׁנִים
מְשָׁרֶתֶת וְעוֹשָׂה בִּשְׁבִילֵנוּ
וַאֲנִי יָצָאתִי מִתּוֹךְ הַגּוּף
וְיָשַׁבְתִּי עַל קְצֵה הַמִּטָּה
הִסְתַּכַּלְתִּי בּוֹ
וְעָלִיתִי לְלַקֵּק אוֹתוֹ
לְלַטֵּף אוֹתוֹ
לְטַפֵּל בּוֹ.

Outside the Body

The hypnotist visited me
She talked about the body which
Is tired from all the years
Serves and does for us
And I came out of the body
And sat at the edge of the bed
I looked at it
And got up to lick it
To caress it
To nurse it.

Yona Wallach, 1992
(my translation)

Yona Wallach, the Israeli poet who wrote this poem, died of breast cancer in 1985. While in her early forties, she was diagnosed as having advanced, metastatic breast cancer. She chose, however, to deny the symptoms and later even the diagnosis until it was too late. Yona Wallach left poetry of a special nature - full of love, passion and vitality of life. Since her death her poems have become famous in Israel, and she herself a legend.

A most notable point about Yona Wallach's writing is that she wrote nothing directly mentioning her illness. Even in her last pieces of work when she was already confined to her hospital bed, such as in the poem quoted, she did not mention the word cancer in her poetry. This is an example emphasising the difficulty that women may face when confronting cancer. Using the word cancer to face the terrible diagnosis can be extremely painful. Yona Wallach, like many other cancer victims, has made a clear decision not to face her diagnosis in a direct manner. I would argue, however, that she faced the cancer indirectly in a non-conventional and special sense. As described in the above poem, Yona Wallach exposed herself to her body and acknowledged its changes and problems. Looking at it as if it were a separate wounded and beloved entity needing to be licked, caressed and cared for, was her way of confronting her illness. She chose to deal with the cancer which grew inside her in the form of hypnosis. Stepping outside her body was her method.

It is only recently that the actual experience of breast cancer has received serious professional attention. This study is founded on the grounds of valuing the personal experiences of women with breast cancer. It is also closely influenced by my own encounter as a woman and a nurse with this disease. It was in my work as a staff nurse on a general surgical ward in a hospital in Jerusalem, that I met women with breast cancer like Yona Wallach. Some were more willing to talk about their illness than others. The impact, however, of the experience of breast cancer for each of these women was profound. Each woman is unique, and one can never fully enter the inner world of the other. In this study, however, I wish to come as close as possible in understanding the personal experiences of women who are confronted with breast cancer and who faced, like Yona Wallach, a decision as to the way they chose to deal with their illness and its treatment. Furthermore, the views of the nurse counsellors regarding the women's decision-making process and their understanding of their role as specialist breast care nurses, will add further insight into the area researched.

An Overview and General Focus of the Study

The significance and magnitude of the problem of breast cancer cannot be over-emphasised. Figures demonstrating the incidence of the disease in the western world are alarming. The United Kingdom leads the world with the highest rate of breast cancer, with Scotland's incidence being most serious. Because of the scope of the problem, much medical attention has been given to the development of treatment for the disease. Unlike a few decades ago, the prospects and prognosis of early stage breast cancer are hopeful, with cure and remission often being attainable. Much of this advancement has been made with the introduction of chemotherapy and radiotherapy and the understanding of the hormonal system in the regulation of the disease.

However, side by side with the development of medical treatment, the hospitals and institutions treating breast cancer patients have become less and less personal and therefore less orientated toward the needs of the individual patient. On the other hand, because of the increasingly impersonal nature of the health care system and the negligence of patients as unique persons, the needs of these patients have become even greater. They find themselves lost and almost anonymous within the complex health system and therefore seek much help and support from the staff around them. There is, furthermore, a growing trend in the provision of health care towards a more market-oriented system. The 'modern' woman of the western world, therefore, is somehow expected to be more involved, aware and demanding of information about the decisions regarding her medical treatment. The treatment of primary breast cancer serves as an example of this situation.

In the light of all this, I argue that there is an increasing need for a recognition and exploration of the individual experiences of patients. Listening to personal views and perceptions of individuals should nowadays be seen as more important than it has ever been before. It is the individual person, not a certain population, that should become the centre of our attention. It is further argued here, that listening also to the personal experiences of nurse counsellors will enrich the understanding of the topic under study.

The focus of this work, therefore, is the woman participating in the choice of her treatment for primary breast cancer. An insight into this particular point will be helpful in understanding the woman who is faced with the very difficult task of deciding, for example, if her breast should be preserved or removed. Looking at the decision-making process itself will serve as a means for entering the experience of breast cancer as a whole. Since the focus is on the women themselves, they will be referred to in the succeeding chapters mainly as women and not as patients. This is to emphasise that their unique reality as women is of even greater significance than that of being a patient. The nurse counsellors who accompany the women throughout the decision-making process will also be looked at.

Nurses, who are in daily and often informal personal contact with the patient, have the privilege of occupying a unique position of responsibility and care for women with breast cancer facing what can be a very traumatic decision-making conflict. The task of counselling, therefore, could legitimately be expected to fall within their orbit. The role of the breast care nurse counsellor, however, has not been clearly defined. In order to do so, the emotional and psychological needs and reactions of women with breast cancer, as they experience them, have to be studied. The observations published in recent years indicate that the mental reaction of women with breast cancer to the disease, and to the available choice of surgical and medical intervention, is highly individual and has no correlation to identifiable factors such as age, familial state or social background. Yet, the study of the psychological problems concerned with conflicts of decision-making and coping with breast cancer has almost exclusively been confined to comparative statistical population analyses. The individual mental processes and trauma involved in making life decisions concerning treatment for breast cancer and the possible modes of adaptation of nursing counselling to the individually varying needs have not been determined. The few qualitative studies in this field have been conducted in North America. In Europe in general, and in the UK in particular, these questions have not yet been addressed by nursing research.

Several researchers have stressed the importance of counselling women with breast cancer in the decision-making process. For example, Pierce (1985) concluded her doctoral dissertation on the process of decision-making by women in early breast cancer by stating that:

> It is time for attention to be directed toward the needs of patients experiencing decisional conflict or crisis. As this study has shown, a minority of patients have difficulty making therapeutic decisions about their health. But for those who do, the psychological distress resulting from decisional conflict is profound. These patients require counsel, information, and structured intervention to make a choice which brings them comfort. (p.187)

It is the aim of the present study to investigate the possibility pointed out by Pierce (1985), that at least for some breast cancer patients professional counselling may be a prerequisite for developing the ability to cope and reach existential decisions concerning their therapy. The rationale of this work is that the formulation of a counselling strategy requires deep **personal** knowledge of breast cancer patients and nurse counsellors; the patients' fears and anxieties, and the external influences they are both exposed to.

The method used in this study is based on the philosophy of phenomenology which enables the exploration of the phenomenon of decision-making in an in-depth and qualitative manner. This is done in order to achieve an understanding of the experience of decision-making from the women's and the nurse counsellors' point of view.

Some Background Comments

Women experiencing primary breast cancer are exposed to an extremely stressful situation. The degree of stress experienced may be determined by a combination of a number of factors, some of which are:

Life history, including educational and environmental background.

Individual beliefs and attitudes towards health care in general, including views about early screening and detection.

The specific diagnosis of cancer - the stage and degree of spread.
Available family and social support systems.

Personality type and the sort of coping strategies usually employed.

Attitudes to body image, feelings of femininity and sexual identity and the importance of the breasts to these.

Many women diagnosed as having early stage breast cancer are given the choice of treatment between, for example, mastectomy (the removal of the breast) and lumpectomy (the removal of the lump) followed by radiation. Other choices can relate to the adjuvant (additional) treatment or to the method of breast reconstruction. The particular point of coming to a decision is itself a stressful phenomenon, which has some basic features in common with all decision-making situations. What makes it special, however, is that it involves such sensitive issues as life and death and feelings of femininity.

Counselling can serve as a method of helping the women diagnosed with breast cancer. This help can reduce their anxiety and encourage the development of coping strategies such as the 'fighting spirit'. Nurses, by the nature of their profession, are in the best position to provide counselling and support for women suffering from breast cancer. This position of nurses has several aspects. One aspect relates to the holistic approach of nursing which views the patient, family, and background as a

whole and does not only focus on one feature or component. Nurses provide physical, social and mental daily care to patients. Another aspect relates to the body of nursing knowledge, which includes an understanding of breast cancer and its medical treatment, as well as counselling and communication skills. Finally, the majority of nurses are women, and as such can more easily show empathy and a better understanding of women with breast cancer, facing a situation which puts at risk their feelings of femininity.

The present study arises, therefore, from the fact that nurses occupy a special position in the health team in providing counselling and support for women with breast cancer. This can be seen as both a challenge and a responsibility for nursing as a caring discipline.

Aim of the Study

The aim of the present work is to gain knowledge of the lived experience of women with breast cancer in order to better understand **what is it like** to make decisions about one's own treatment. The women's perceptions of the support they received from a specialist nursing counselling service will be explored. Further knowledge into the role of the nurse counsellor will be gained by an examination of the specialist nurses' views and ideas. Ultimately, there is an intention to develop a strategy for breast care counselling that is practical, meaningful and designed to meet the personal requirements of the individual woman.

The Research Questions

In order to understand the lived experience of women facing decisions relating to their treatment for breast cancer and the nursing counselling role, some specific research questions were developed. These questions were:

How do the women experience the decision-making process regarding their treatment?

What are the perceptions of women and nurse counsellors concerning the personal risks and gains related to the participation in the choice of treatment?

Which are the women who wish to take an active role in the decision-making regarding their treatment? and, which are the women who prefer that the choice be made for them?

What factors and motives do women see as most influential when making a choice of treatment? How do the nurse counsellors understand these factors?

How do women perceive the general help and support they received from the nursing staff?

What is the responsibility of the nurse counsellor, as viewed by the women and the nurse counsellors themselves, in helping the women through the decision-making process? How do they perceive counselling both in general and as a support at that situation?

Chapter II:

BREAST CANCER - A Review of the Literature

The Medical Treatment of Primary Breast Cancer

Breast cancer is the most common cancer among women in the western world, and is the most common cause of death in women aged 35-55. An individual woman stands a one in twelve chance of developing the disease, and there is evidence that the annual incidence and overall mortality rate is increasing throughout the western hemisphere. Twenty-four-thousand new cases are diagnosed each year in the United Kingdom where more than 15,000 women die from breast cancer annually. Despite these gloomy statistics, breast cancer does have a moderately good prognosis, especially in its early stages. The five-year relative survival rate is 62% which makes breast cancer one of the 'best prognostic' cancers.

Primary Therapy: Mastectomy and Lumpectomy Plus Radiotherapy

The traditional treatment for breast cancer has been mastectomy (the removal of the breast) in its various forms. This has also been the treatment for early stage disease with a tumour less than four centimetres in size and no axillary node involvement. The development in radiation techniques during the last two to three decades has made it possible to introduce lumpectomy as an alternative curative method for early stage breast cancer, since it must be usually followed by radiotherapy. Because of the psychological impact of these alternative treatments, it is important to understand the difference between the various types of mastectomy and lumpectomy in terms of the amount of breast tissue lost. The New-York State Health Department defined in 1985 these different surgical techniques as:

> **Lumpectomy**: the removal of the cancer and a margin of healthy tissue, a procedure which spares the breast. It is generally followed by radiation therapy, to reduce the recurrence of disease.
>
> **Segmental Mastectomy**: the removal of the cancer and more of the surrounding breast tissue, while sparing most of the breast. (The

term quadrantectomy is used when one quarter of the breast is removed).

Simple Mastectomy: (Also called total mastectomy) the removal of whole breast (including the nipple) without removing lymph nodes from the armpit.

Modified Radical Mastectomy: the removal of the breast and most of the lymph nodes in the armpit.

Radical Mastectomy: the removal of the entire breast, the axillary lymph nodes and underlying muscles of chest wall. It is indicated in only a small number of cases today.

(Deming, 1988, p.41)

From a UK perspective, Prof. Baum in his book Breast Cancer - the Facts (1988) provided the following description of the different mastectomies available as a surgical treatment for primary breast cancer.

Simple Mastectomy - removes all the breast tissue including the axillary tail and including an ellipse of skin containing the nipple and the areola. It is now conventional to take small samples of a few of the lowermost axillary lymph nodes that are conveniently to hand at the termination of this procedure. The elliptical skin incision is then closed as a transverse line.

Modified Radical Mastectomy - again removes all the breast tissue, but in addition removes the pectoralis minor muscle, thus gaining ease of access to the armpit so that all its contents, which include the lymph nodes within a pad of fat, may be cleaned out. After the operation the retention of the pectoralis major, and the transverse linear scar, make it impossible to distinguish from the simple mastectomy.

Classical or Halsted Radical Mastectomy - removes the pectoralis major and pectoralis minor muscles and all the axillary lymphatic tissue. Postoperatively there is a concavity beneath the collar-bone where the ribs, which are normally covered by the pectoralis muscles, can be seen.

(Baum, 1988, p.23).

Margolese (1988) commented that:

> One of the great surgical controversies of the twentieth century has been the choice of operation for primary breast cancer. For fifty years there was virtually unanimous agreement in favor of the Halsted radical mastectomy. The last twenty years has been a period of considerable uncertainty, from which has developed a trend for less radical surgical intervention. (p.11)

Whatever the extent of the original surgery for primary breast cancer, the addition of radiotherapy to the chest wall and the regional lymph nodes seems to improve the degree of local control of the disease. Radiotherapy is usually commenced immediately after the operation for up to six weeks, with three sessions each week. The usual treatment dose is between 3500 and 4500 rads. The areas treated may include the tumour bed, chest wall, skin flaps and lymphatic draining areas such as the axillary, parasternal, supraclavicular and intraclavicular lymph nodes. After irradiation a proportion of cells will die, a proportion will be damaged and some will recover. Treatment is given over a period of time to allow normal cells to recover, reducing damage (Lawton and Twoomey, 1991, p.53). Radiotherapy is given to all women who have lumpectomy (unless there is a contraindication for doing so) and to some women who have mastectomy whose axillary lymph nodes where found to be positive for cancer cells. Some side effects of radiotherapy may be malaise and nausea, and fair skinned women may experience severe skin reactions.

The benefit of radiotherapy in terms of preventing local recurrence of the disease is, however, still under medical debate. Many trials are in progress for evaluating its effectiveness. The debate is especially concerned with whether radiotherapy should be given as a preventive measure to all women or whether it should be delayed until recurrence has been confirmed. Nevertheless, some conclusions concerning radiotherapy in relation to the extent of breast surgery have been drawn:

1. Radical mastectomy followed by radiotherapy is equivalent to simple mastectomy followed by radiotherapy.

2. Radical mastectomy alone has a higher incidence of local recurrence than radical mastectomy followed by radiotherapy.

3. Simple mastectomy alone has a higher incidence of local recurrence than simple mastectomy followed by immediate radiotherapy.

4. Delayed radiotherapy following either simple or radical mastectomy is likely to produce adequate control in the majority of cases when recurrence occurs.

5. The more extensive the primary surgery, the more difficult the rehabilitation of the woman; in particular the incidence of severe lymphoedema (swelling caused by excess fluid) of the arm is highest after radical surgery combined with postoperative radiotherapy and lowest after conservative surgery alone.

6. In carefully selected cases 'lumpectomy' plus radiotherapy will produce adequate local control without hazarding survival.

(Baum, 1988, p.69)

A large clinical trial done in the US has demonstrated that the overall five and ten year survival rates following lumpectomy and mastectomy are similar (Fisher, Bauer and Margolese et al., 1985). This, and similar findings, reported by Williams and Buchanan (1987) as well as Eich (1988), made the less mutilating and less disfiguring lumpectomy an attractive choice of treatment for early stage breast cancer.

The factors which may influence the medical choice of treatment include the patient's age and menopausal state, tumour size, local extension and spread to the regional lymph nodes as well as the presence of distant secondary tumours. The randomised trial conducted by Fisher et al. (1985) evaluated breast conservation by segmental mastectomy (lumpectomy) in the treatment of stage one and stage two breast tumours smaller than four centimetres in size. One-thousand-eight-hundred-and-forty-two patients were randomly assigned to total mastectomy, segmental mastectomy alone or segmental mastectomy followed by breast irradiation. All patients had axillary node dissection, and those with positive nodes received chemotherapy. The long-term results indicated that treatment by segmental mastectomy, with or without breast irradiation, gave 'disease-free', 'distant-disease-free' (metastasis-free) results and overall survival at five years that were no worse than after total breast removal. The

conclusion of this study was that segmental mastectomy followed by breast irradiation, and additional chemotherapy in women with positive nodes, was the most appropriate therapy for stage one and stage two breast tumours smaller than four centimetres, provided that the margins of resected specimens are free of tumour.

Such results influenced the surgeons in their choice of treatment for early stage disease. An example of this influence can be seen in the findings of a questionnaire survey of consultant surgeons in the UK, which indicated that only 39% of the surgeons tended to perform mastectomy whereas 64% would perform conservative surgery for primary breast cancer (Morris and Royle, 1988).

As a result of such developments the second King's Fund Forum in 1986, which concerned itself with the management of breast cancer, published a consensus statement. This read that:

> There is no evidence that mastectomy or more extensive surgery, as opposed to local removal of the tumour, leads to longer survival. The risk of local recurrence is greater with breast conservation. However, this risk can be reduced substantially by radiotherapy although there is no evidence that radiotherapy prolongs life. (King's Fund Forum, 1986, p.946)

Adjuvant Systemic Therapy

Adjuvant systemic therapy for breast cancer may be defined as: "a treatment, usually cytotoxic agents and/or endocrine therapy, aimed at eradicating or arresting occult micrometastatic disease. Such therapy may be administered before, during or in a timely manner after local therapy" (Goodman, 1991, p.175).

Adjuvant Hormonal Therapy - The types of adjuvant endocrine therapy that have been evaluated in the past or are in the process of current evaluation are oophorectomy (removal of the ovaries), irradiation of the ovaries, 'chemical adrenalectomy' (inhibition of the adrenal gland using corticosteroids), and anti aestrogen therapy.

Much current interest has been generated by the new group of drugs referred to as the anti-aestrogens, of which Tamoxifen (Nolvadex) is perhaps the most effective and least toxic. This drug works by competing for the binding site on the estradiol receptor of the tumour cells (Baum, 1988).

Adjuvant Chemotherapy - Chemotherapy involves the use of agents known as cytotoxic drugs that damage all growing cells. The majority of ongoing trials of systemic chemotherapy are using combinations of cysotoxic drugs given in cycles at approximately monthly intervals for up to two years after surgery. Examples of such combination chemotherapy are Cyclophosphamide, Methotrexate and 5-Fluorouracil (known as CMF), Methotrexate, 5-Fluorouracil and Leucovorin (MF+L) or, Cyclophosphamide, Doxorubicin and 5-Fluorouracil (CAF).

The primary goal of adjuvant therapy is to significantly prolong survival while maintaining an acceptable quality of life. Goodman (1991) explained that three questions are important in evaluating whether this goal is met by a specific treatment:

> - What is the effect of therapy on overall survival?
> - What is the effect of therapy on disease-free survival? Prolonged periods of disease-free survival are considered advantageous assuming quality of life to be better before than after relapse.
> - What is the effect of therapy on quality of life? (p.175)

She further observed that the potential benefits of therapy are balanced against both short-and long-term side effects, as well as the psychological, social, and economic problems a woman might experience as a result of treatment (p.175).

Prognostic Factors

In an attempt to identify those women at higher risk of relapse after primary therapy, a number of possible prognostic markers have been studied. Such information may be especially helpful in delineating those women with node-negative disease at highest risk of recurrence, and, therefore, most likely to benefit from adjuvant systemic therapy.

Tumour Size - Studies have shown that tumour size alone or, at best, in combination with other prognostic factors is critical in deciding therapy for many women. Goodman (1991) summarised such studies and showed that in tumours smaller than 2 cm the 5 year relapse rate in node-negative patients is 8-13 %, whereas for women with a tumour greater than 2 cm it is 19-24 %.

Nodal Status - Axillary lymph node status is an equally important prognostic indicator in breast cancer. Microscopic examination of a minimum of 6 to 10 nodes is used to ensure proper staging. If more than 10 nodes are involved, each additional involved node adds to risk of relapse. Goodman (1991) in her account of adjuvant therapy for breast cancer, summarises that at ten years, where there was no node involvement, there was a 10-35 % chance of recurrence, with 1 to 3 involved nodes the chance of recurrence was a 55-65 %, and more than 4 positive nodes resulted in an 80-90 % chance of recurrence.

Oestrogen Receptor Status - The presence of oestrogen receptores (ERs) in primary tumours has been associated with a favourable prognosis because it has been presumed that it reflects a more differentiated tumour. Receptor-positive tumours are generally associated with a longer disease-free interval and overall survival rates.

Histologic and Nuclear Grade - Histologic grading is a means of depicting the architectual arrangement of cancer cells and the mitotic rate. In general, poorly differentiated tumours have a high histologic grade and are associated with a relatively poor prognosis. Nuclear grading is a pathological method of estimating the differentiation of the nuclei of the cells rather than the architecture of the cell. Nuclear grading has been shown to be an independent prognostic indicator.

Other prognostic indicators include factors on the molecular level such as Proliferative Rate and DNA Ploidy, HER-2/neu oncogene and Epidermal Growth Factor Receptors. These will not be elaborated in the present review, but should, however, be mentioned.

In 1985 the National Institutes of Health (NIH) held a consensus development conference on adjuvant therapy for breast cancer. Based on the results of research data available at that time, the panel suggested that:

> 1) Combination chemotherapy should be standard therapy for all premenopausal node-positive patients regardless of hormonal receptor status.
>
> 2) For premenopausal node-positive women, adjuvant endocrine therapy (tamoxifen or ovarian ablation) either alone or in combination with chemotherapy, is not recommended as standard therapy.
>
> 3) Postmenopausal women with positive nodes and positive hormone receptor levels should be treated with tamoxifen.
>
> (Goodman, 1991, p.176)

The recommendations indicated that the benefits of adjuvant chemotherapy in the treatment of post-menopausal women were not well defined and could not be recommended as a standard treatment approach. However, in receptor-negative women, adjuvant chemotherapy should be considered, especially in women with four or more positive axillary nodes.

In 1990, the NIH convened another consensus development conference which concentrated on the treatment of early stage breast cancer. Although the international experts could not easily reach agreement on the optimal approach to the systemic management of breast cancer, the following guidelines were drawn up:

> 1) Because there are many unanswered questions concerning the adjuvant systemic treatment of node-positive breast cancer, all patients who are candidates for clinical trials should be offered the opportunity to participate.
>
> 2) The decision to use adjuvant treatment in node-negative women should follow thorough discussion with the patient concerning the likely risk of recurrence without adjuvant therapy, and its effect on quality of life.
>
> 3) While all node-negative patients have some risks of recurrence, the majority are cured by local therapy alone.

4) all node-negative patients with tumours of less than or equal to 1 c'm have an excellent prognosis and do not require adjuvant systemin therapy outside of clinical trials.

(Goodman, 1991, p.176)

The value of adjuvant systemic therapy has been clearly demonstrated in both node-positive and node-negative patients. The identification of the subjects for whom these treatments are most useful and dose intensity and questions regarding the schedule are subjects of current research both in the laboratory and in clinical practice. The interaction between adjuvant chemotherapy and adjuvant endocrine therapy is also being further explored.

The review of the current medical treatment of primary breast cancer demonstrates the complexity of the different methods of therapy and the controversy over the preferable treatment in terms of survival. The relatively straight forward surgical procedure of mastectomy is now being replaced or accompanied by other more sophisticated treatment modalities such as chemotherapy, hormonal therapy and radiotherapy. Factors like axillary node involvement, oestrogen receptors and menopausal state have an important element in the medical choice of treatment and estimated prognosis. Moreover, the diagnosis of primary breast cancer may no longer represent a specific disease, but is nowadays seen as an 'unbrella' term for a group of more clearly defined types of early stage breast cancers.

It may be concluded that the medical world is still experiencing an uncertainty concerning the treatment of primary breast cancer. Many developments are recent and are still in progress. It is no wonder, therefore, that women with primary breast cancer may find themselves confused and overwhelmed with the information about their diagnosis and treatment. Furthermore, the recognised psychological issues associated with the illness and the growing attention to the idea of Quality of Life has added considerable complexity to the understanding of the disease and the choice of treatment.

The Psychosocial Aspects of Breast Cancer

In view of the dramatic psychological implications both of breast cancer and its treatment, mechanisms of psychological coping have proved vital in the treatment of primary disease. The psychological impact of mastectomy and adjustment to its results have been extensively discussed in the literature (Asken, 1975; Polivy, 1977; Ray, 1977; Jenkins, 1980; Carrol, 1981; Feeley, Peel and Devlin, 1982; Twamey, 1987; Anderson, 1988; Dunn, 1988; Jamison, Wellisch and Pasnau, 1988). The breasts have always been a symbol of femininity and consequently the removal of the breast can have a profound effect on the woman's body image, sexual identity and feminine feelings. Breast cancer and mastectomy and their effects on the woman have been, therefore, the subject of much psychosocial research.

The psychological threat that the diagnosis of breast cancer poses for the individual woman has also been widely discussed (Greer, 1979; Ray and Baum, 1985; Schain, 1987; Fallowfield and Baum, 1988; Fallowfield, 1990, 1991). This existential threat results from the vivid reality of cancer and death, the possible loss of a breast, and the adverse effects of accompanying treatments such as chemotherapy and radiotherapy.

In the following section specific psychosocial research literature on breast cancer, that was found to be relevant to this study, will be reviewed. The review includes literature found primarily through the CD 'Medline' and 'Psychlit' data bases updated up to Nov. 1993. It should be noted, that the majority of the studies that will be referred to in this section employed statistical methods of analysis and were based on a quantitative approach. The critique that will be offered will therefore concentrate on this line of thought, and may not be relevant when criticising studies which made use of a more qualitative, interpretive, phenomenological method.

Issues surrounding early screening for psychological morbidity will be dealt with first. A section on different mechanisms for coping with cancer will follow. This will include a review of the psychosexual aspects of breast cancer. Further, the psychological implications of the choice between mastectomy and lumpectomy will be discussed. This area

includes studies that evaluated the psychological benefit of giving women the choice of treatment, studies that examined the factors that affect the woman's decision-making, and other works that evaluated the psychological adaptation to, and consequence of, both treatments: mastectomy and lumpectomy. The section ends with a review of the literature discussing the effect that breast cancer may have on the partner/husband and other family members, especially the daughters.

Screening and Detection for Psychological Morbidity

Early screening for physical symptoms of breast cancer is a well established aspect of modern medical care. Women are encouraged to practice routine breast self examination (BSE), to regularly visit their physician for physical examinations, and to be screened by having a mammogram. These screening methods have been developed in order to 'catch' the tumour as early as possible. Early tumour diagnosis has been shown to improve treatment results in terms of remission and survival (Nash, 1984; Forrest, 1987; Nettles-Carlson, 1989).

Psychiatric studies have shown that screening for psychological morbidity and its early detection are in a similar way important for the prognosis of the psychological treatment and for the eventual psychological state and well being of the patients (Gordon, Freidenbergs, Diller, Hibbard, Wolf, Levine, Lipkins, Ezrachi and Lucido, 1980; Watson, Denton, Baum and Greer, 1988). Watson (1991) further points out that physicians often fail to detect, or inaccurately detect, patients with significant psychological morbidity. Others (Sensky, Dennehy, Gilbert, Begent, Newlands, Rustin and Thompson, 1989) add that this may not be a failure in recognition of symptoms but rather a failure to acknowledge them. Maguire (1983) has given a number of screening questions to be used at follow-up clinics. These questions, he suggested, can be asked selectively within the context of an informal consultation in the clinic:

> How have you been feeling since the operation?
> How have you been sleeping?
> Have you found it easy to adapt to everyday life?
> Do you often feel especially miserable or worried?
> Are you as active socially as you were before surgery?

What about your relationship with your husband (partner); has that been affected?
Have you resumed love-making yet?
How do you feel about your breast?
How do you feel when you catch sight of your chest?
Have you had any pain?
Are there any other problems?

(Maguire, 1983, p.21)

As Watson (1991) described, it is possible to be sensitive to patients at risk and monitor them closely in follow-up clinics. Early psychological intervention is in the best tradition of preventive medicine because not only does it allow early formulation of a management policy, but also an improved chance of reducing psychological morbidity. Factors which have been associated with increased risk of psychological morbidity are:

* Psychiatric history.
* Lack of support from family or friends and no opportunity to confide worries.
* Pre-existing marital problems.
* Cancer development and treatment associated with visible deformity.
* Inability to accept the physical changes associated with the disease or its treatment.
* Age, whereby younger patients are more susceptible.
* Tendency to suppress or contain negative emotions.
* Low expectation of the efficacy of the treatment.
* Lack of involvement in satisfying activities, no vocational or recreational occupation.
* Awareness of additional physical symptoms following the diagnosis of cancer, regardless of the actual stage of the illness.
* Adverse experience of cancer in the family.
* Treatment by aggressive cytotoxic drugs.
* Additional concurrent stress.

(Watson, 1991, p. 226)

Early screening and detection for psychological morbidity can enable the health care team to plan the provision of intervention that will enhance effective adaptation. Counselling and support by a specially trained nurse

is an example of such an intervention that is aimed at facilitatating positive coping.

Coping Mechanisms with Cancer

Life stresses elicit not only emotional reactions, but also prompt coping. Coping refers to active responses aimed either at minimising the actual threat by instrumental means or at reducing its impact "palliatively". The latter can be achieved either by reappraisal of the threat or by a modification of the emotional reaction to it without any change in the objective or subjective situation. A variety of coping mechanisms is applicable to the cancer patient whereby the attempted coping strategy is mainly influenced by the personality type. Ray and Baum (1985) described six categories of coping mechanisms:

> **Rejection - Assertion**: reflecting a view of the situation as unacceptable and a violation of the patient's needs and expectations, leading to an active and sometimes hostile attempt to change the threatening circumstances.
>
> **Control**: where the situation is seen as a challenge, and the patient attempts to deal rationally with problems from this perspective.
>
> **Resignation - Helplessness**: where the patient again faces the threat but sees herself as relatively powerless, with events and their outcomes being determined by fate.
>
> **Dependency**: reflecting a reliance on others. The patient sees herself as helpless but turns to others, or to God, as a source of support.
>
> **Avoidance**: where the patient basically acknowledges the threat, but avoids situations or thoughts that make this salient for her.
>
> **Minimisation - Denial**: where the threat is minimized or disavowed.
>
> (Ray and Baum, 1985, p.37)

The relative adaptiveness of specific strategies depends on the objective circumstances and on the person's needs and resources. It is often assumed, for example, that denial is maladaptive, since it distorts reality,

although its value should in fact be appreciated in the context of the patient's circumstances. Denial can, in some instances, protect the patient against distress at little personal cost.

Weisman (1979) studied the effect that coping ability and coping strategy may have on the survival and quality of life of cancer patients. He consequently developed an advisory list for facilitating what he defined as positive coping by cancer patients. His list included the following ten points:

1) Avoid avoidance; do not deny.
2) Confront realities, and take appropriate action.
3) Focus on situations, or redefine a problem into solvable form.
4) Always consider alternatives.
5) Maintain open, mutual communication with significant others.
6) Seek and use constructive help, including decent medical care.
7) Accept support when offered; be assertive, when necessary.
8) Keep up morale through self-reliance or resources that are available.
9) Self-concept is important as symptom control.
10) Hope is self-pride, not self-deception.

(Weisman, 1979, p.43)

Benner and Wrubel (1989) criticise Weizman's conclusions. Inherent in his theory, they explain, are problems of using a normative model. Weisman proposed that there is a 'good' way to cope with cancer and a 'bad' way. However, Benner and Wrubel argue that categorising coping strategies as 'good' or 'bad' is of limited value since the actual concerns and situation of the individual person are not taken into consideration. In their opinion, Weisman's approach produces trivial lists of advice that offer little guidance and show little understanding of what that advice might mean to specific people in specific situations.

They further argue that lists of advice are deceptively simple, they tend to miss the real issues involved, trivialise the demands on the patient, and overlook the loss which the patient has suffered and the fears still hanging over her life. Such lists of advice reflect the naive assumption that there can be rules for effective coping. It is assumed that the patient or medical consultant will recognise the applicable advice for a particular situation

and what form the consequent coping strategy should take. It also assumes that the person has the ability to follow the advice. The item 'accept support when offered; be assertive, when necessary' is a good example of false advice being made on these wrong premises, say Benner and Wrubel. "Any rule or general directive can play havoc when applied in ways that do not take into consideration the patient's world, skills, history, concerns, and current circumstances" (Benner and Wrubel, 1989, p.105).

Greer, Morris and Pettingale (1979) undertook one of the most extensive studies on the effect of the different coping mechanisms of breast cancer patients on the outcome and the progression of the disease. They have grouped the patterns of response to diagnosis of breast cancer into four mutually exclusive categories. The coping pattern was assessed by asking patients how they perceived the nature and seriousness of their disease and how their lives had been affected by it. The psychological response was categorised according to patients' verbatim statements and accompanying mood. The categories were:

> **Denial** - apparent active rejection of any evidence about diagnosis which might have been offered, including the evidence of breast cancer. Such patients were usually extremely guarded in their replies and restricted discussion of the subject. They neither showed nor reported emotional distress.
>
> **Fighting spirit** - a highly optimistic attitude, accompanied by a search for greater understanding and knowledge about breast cancer. These patients look for information and plan to do everything in their power to 'conquer' cancer. No distress is reported.
>
> **Stoic acceptance** - acknowledgement of the diagnosis without inquiry for further information. Such patients ignored the illness and any symptoms as far as possible, and carried on normal life. Distress is lowered by the stoic attitude.
>
> **Feeling of helplessness/hopelessness** - a complete engulfment by knowledge of diagnosis. These patients regarded themselves as gravely ill and sometimes as actually dying. These patients showed high levels of emotional distress.
>
> (Greer et al., 1979, p.786)

This prospective study which started in 1972 followed the patients for fifteen years. During these years another category of coping with cancer was added. This category was defined as 'Anxious Preoccupation'. It was originally included under Helplessness/Hopelessness, but was subsequently shown to be an independent factor:

> **Anxious Preoccupation** - Patients react to the diagnosis with marked and persistent anxiety. They seek information about cancer but tend to interpret it pessimistically; they may seek cures from a variety of sources including so-called alternative treatments. They monitor their bodily sensations closely, interpreting aches and pains as probable signs of spread or recurrence of cancer... Fears of recurrence of the disease occupy these patients and disrupt their lives.
>
> (Greer, 1991, p.44)

This study reported a statistically significant association between the patients' psychological response three months after the confirmation of the diagnosis of breast cancer and their long term survival. Patients who responded with a 'fighting spirit' or 'denial' had significantly better five, ten and 15-year survival rates than patients who adopted a fatalistic response or one of helplessness or hopelessness. It was demonstrated in this work that at least in terms of survival, denial has positive adaptive value as a coping mechanism for cancer. This might contradict the more common view of denial as a negative defence mechanism.

Greer (1991) in summarising this study gives the following provisional conclusions:

> 1) On balance, the available evidence supports the hypothesis that the psychological stance which patients adopt towards their disease can affect the course of certain cancers. This conclusion applies to early stage, non-metastatic cancers. The evidence in patients with metastatic disease is equivocal.
>
> 2) Passive and helpless/hopeless responses are consistently associated with poor outcome. The opposite response to helplessness, i.e. fighting spirit, has been insufficiently studied but with the exception of one report appears to be correlated with a longer duration of survival. The other active coping response originally called denial but which is more accurately termed

positive avoidance is also associated with longer duration of survival. (p.47)

In the light of this work, Moorey and Greer developed a psychological intervention method with the aim of enabling patients with passive, helpless responses to adopt active, fighting spirit coping strategies. This devised intervention is termed Adjuvant Psychological Therapy (ATP).

> Adjuvant Psychological therapy is a brief, problem-focused therapy with two main aims:
> 1) To reduce anxiety, depression and other psychiatric symptoms.
> 2) To improve mental adjustment to cancer by inducing a positive fighting spirit.
>
> Four broad strategies are used to achieve these aims:
> 1) Encouraging open expression of feelings.
> 2) Promoting in patients a sense of personal control over their lives and active participation in the treatment of their cancer.
> 3) Helping patients to develop effective coping strategies for dealing with cancer-related problems.
> 4) Improving communication between the patients and their partner or spouse.
>
> (Moorey, 1991, p.97)

The main components of APT are ventilation of feelings, behavioural and cognitive techniques.

In 1992 Greer, Moorey, Baruch, Watson, Robertson, Mason, Rowden, Law and Bliss reported a study which tried to determine the effect of Adjuvant Psychological Therapy on the quality of life of cancer patients. The study was a prospective randomised controlled trial comparing the quality of life of patients receiving psychological therapy with that of patients receiving no therapy, measured before therapy, at eight weeks, and after four months of follow-up. A sample of 174 patients with cancer were studied. Only about 50% of the patients had breast cancer. The outcome measures used were the Hospital Anxiety and Depression Scale, Mental Adjustment to Illness Scale, Rotterdam Symptom Checklist and the Psychosocial Adjustment to Illness Scale.

They found that at eight weeks, patients receiving therapy had significantly higher scores than control patients on fighting spirit and significantly lower scores on helpless, anxious preoccupation, and fatalism; anxiety; psychological symptoms; and an orientation towards health care. At four months patients receiving therapy had significantly lower scores than the controls on anxiety; psychological symptoms; and psychological distress. They concluded that: "APT produces significant improvement in various measures of psychological distress among cancer patients. The effect of therapy observed at eight weeks persists in some but not all measures at four months follow-up" (Greer et al., 1992, p.677).

Other examples of psychological interventions designed to facilitate positive coping in patients diagnosed with cancer are:

The Simonton Approach - The basic philosophy of the Simonton approach maintains that the development of cancer involves a number of independent psychological and biological processes, and that these processes can be recognised and understood. It is also thought that the sequence of events which lead to illness can be reversed to lead the organism back into a healthy state. This approach makes use of relaxation and visual imagery techniques designed to enhance a patient's immune response as a method of dealing with the disease (Simonton, Simonton and Creighton, 1990).

Crisis Intervention and Group Therapy - are designed to enable patients to share and express their feelings and emotions concerning the disease, and help them express their anger and hostility in a group situation (Kfir and Slevin, 1991).

The questions 'what is effective coping with breast cancer?' and 'how can effective coping be facilitated?' are difficult to answer and are still being explored in current studies. One of the clear conclusions from the existing research literature is that active coping involving a control over the situation is of psychological benefit. Furthermore, the effect that the diagnosis of breast cancer may have on sexual adjustment is an important element in general psychological coping.

Sexual Adjustment

The sexual aspects related to the diagnosis and treatment of breast cancer have received limited attention in the literature (e.g. Woods, 1975; Woods, 1979; May, 1980; Bransfield, 1882; Auchincloss, 1989; Kaplan, 1992). Most of the literature looked at these issues from the framework of general adaptation to the disease. For example, in studies that compared the psychological consequences of both lumpectomy and mastectomy, the topic of sexuality was looked at only as part of general psychological adaptation. This will be referred to later on in this chapter.

In a review of factors affecting sexual adjustment, Bransfield (1982) grouped them into biological, psychological, sociocultural and partner variables.

Biological variables: Include age, menopausal status, cancer stage, treatment regimes, level of physical impairment and level of pain in the operated area. Age itself is not a predictor of sexual behaviour, but may give an indication of the woman's general health and partner availability. The loss of a breast appears to be less upsetting to older women, but whether age has an effect upon sexual adjustment after mastectomy is unknown. Other physiological factors which may affect sexual functioning include alcohol and drug abuse and the existence of concurrent illness.

Psychological variables: Almost all authors have mentioned that multiple factors, such as body image, self-esteem, sexual identity, femininity and mood play a role in the re-establishment of sexual life. Body image, or the self-perception, satisfaction and comfort with one's own body, appears to be closely related to sexual functioning. Sexual and feminine identity are at risk for the breast cancer patients, with the 'more feminine' patient being the most vulnerable.

Sociocultural variables: To a limited extent, the dependence of the sexual functioning of the patient with breast cancer on their marital status, relationship and sexual satisfaction has also been examined. Almost all breast cancer patients are married although 17-35% of the general female population is unmarried, widowed or divorced. The existing information

suggests that unmarried women may have more difficulties in resuming sexual relations following breast cancer treatment.

Partner variables: Only a few studies have researched the male's psychosexual response following his partner's treatment for breast cancer. A large number of personal and demographic variables may influence the attitude of the male partner toward a female partner suffering breast cancer. Age, culture, religion, income, education, duration of marriage, marital and sexual satisfaction, frequency of intercourse, extramarital affairs, and the participation of the partner in decision-making have been considered. They included one interesting correlation that may deserve special attention. Men who were more involved in the decision-making process regarding the choice of treatment for their wives enjoyed more sexual satisfaction both before and after the treatment, than men who were less involved. Sexual frequency was correlated with sexual satisfaction. These results imply that husbands who primarily have a close and warm relationship with their wives are likely to share their wives' emotional and decision-making problems, and continue to do so also after the mastectomy.

Vaeth (1986) described the following effects that cancer may have on sexuality:

> The process of cancer, the illness per-se, brings with it the symptoms, at some stages, of weakness, malaise, a lack of energy, these affect sexuality.
>
> The personal process of accepting the diagnosis of cancer and the generalization of thought that accompany such a diagnosis, 'Am I going to die... soon?' affect sexuality.
>
> The effects of the treatment: surgery, the radiation, the chemotherapy and the immunotherapy; these affect sexuality. Some forms of treatment cause hair loss, anorexia, nausea, vomiting, extreme weakness and sterility; these therefore also affect sexuality.
>
> The resultant damage of the disease or treatment on the physical appearance and self-image can affect sexuality, that is how the person sees herself, and how others see the person and how the person sees the self "through the eyes of others" that affects sexuality.

> The family process of accepting the diagnosis of cancer and the expectations, the not knowing, the grieving in anticipation of that time in the future when they must live without that person who has cancer, the grief and the changed, more dependent role of the patient who is not performing the same important family functions, affect sexuality. (p.7)

Auchincloss (1989) provided a detailed review of the literature concerning sexual dysfunction in cancer patients. She discussed sexual issues according to cancer sites: three cancers in men (prostate, penile and testicular) and four in women (breast, cervical, vulvar and ovarian) and two cancers which occur in both sexes: bladder and colorectal. Concerning breast cancer, she identified six main issues of concern related to sexuality:

1) Significance of breast - emotional, sexual.
2) Large number of patients.
3) Appearance concerns - scar, prosthesis, reconstruction.
4) Surgical treatment - loss of breast.
5) Chemotherapy - loss of ovarian function.
6) Young patients - Childbearing possible after treatment.

After reviewing the literature related to sexual issues in cancer, Auchincloss (1989) further suggested guidelines and recommendations for clinicians for promoting sexual rehabilitation in patients treated for cancer. These recommendations included the following seven points:

1. Ask about sex. Avoidence - by staff and patients - is the chief obstacle to sexual rehabilitation.
2. Include the partner whenever possible. The partner's attitudes are crucially important to the patient, and supportive partner makes rehabilitation quicker and easier.
3. Take a positive stance with the patient. Some form of sexual expression is always possible for patients, and helping the patient to feel less anxious will help foster a better sexual response.
4. Take a good sexual history. Evaluate sexual response (desire, excitement, orgasm phases), and ask about pain, fatigue, alcohol, and depression. Consider both medical and psychological aspects.
5. Be prepared to offer:
    * Basic information about human sexual response, and sexual side effects of treatment and medication.
    * Reassurance where there is no true sexual problem.
    * Support and hope where a sexual problem exists.

* Diagnosis and workup of associated medical or treatment-related conditions, including medication change where indicated.
* Treatment of medical causes of sexual dysfunction.

6. When counseling patients on sexual issues, after evaluating the problem and offering information (and workup where indicated), try simple suggestions first, and follow up on these in later visits.
7. Be able to refer patients with persisting sexual problems to a colleague with training and/or experience in human sexuality and sex therapy.

(Auchincloss, 1989, p.399)

This detailed review was proceeded by special reference to three phases of sexual intercourse: Desire, Exitement and Orgasm. The author examined each one of these phases and looked at how they may be affected by cancer. At the end of the chapter she discussed the influence of stress, fatigue, pain and depression - which are common psychological sequelae of cancer - on sexuality.

Kaplan (1992) more specifically, reviewed the various sexual side-effects of the current treatments for breast cancer. She addressed all the side-effects related to surgery of the breast, chemotherapy, radiotherapy and hormonal therapy, and their relation to sexuality. She concluded by saying:

> Women with breast cancer should be fully informed about the risks and benefits of the alternate treatments and preventive measures which are currently available. If women are to make truly informed choices, they must be given accurate and detailed information about the potential sexual side-effects of the various treatment options. (p.15)

Bransfield (1882) argued that the willingness and/or the ability on the part of the health care provider to discuss sexual functioning undoubtedly has an impact on the patient's sexual rehabilitation. This willingness and/or ability is partially related to the practitioner's own sexual knowledge base and his sexual attitudes. It is also related to the amount of practice she or he has had in discussing sexual concerns with patients, and her or his professional education on such issues.

In the light of the effect that cancer may have on sexuality, body-image and feminine identity - the various psychological aspects of both mastectomy and lumpectomy will be further discussed in the following section.

The Psychological Implication of the Choice Between Mastectomy and Lumpectomy

Since new medical developments in the treatment of primary breast cancer have failed to show significant evidence that radical or modified mastectomy is medically better than lumpectomy, the concept of involving the patient in the choice of treatment and letting her make the decision has been established. "If we cannot tell the woman which is the most beneficial treatment - why should she not choose for herself?", was the argument behind it. But how does the woman make this choice?

The Psychological Benefit of Making a Choice and Factors Affecting the Decision-Making

Some authors argue that the psychological distress and morbidity related to the two treatments, mastectomy and lumpectomy, are similar in nature and are associated with the threat from cancer rather than with the threat of losing a breast (e.g. Wilson, Hard and Dawes, 1988; Fallowfield, 1991). Nevertheless, the choice of treatment is a major issue in the treatment of breast cancer. Yet, when conditions allow lumpectomy, the choice between this conservative treatment and the radical treatment is in most cases left to the patient herself. It is important, therefore, to determine how breast cancer patients can be helped to cope with their distress and make an informed and rational decision which best suits their needs. These needs are personal and therefore vary from one woman to another. For one woman, maintaining her outer appearance and body image plays a major role in her adjustment to the disease; whereas for another woman, the trust that radical surgery can remove her cancer is a greater source of hope, and helps her to cope with her condition in the future. In the latter case the psychological impact of losing a breast is of lesser importance than the fear that some neoplastic tissue may have escaped resection.

A breast cancer patient discusses the choice of mastectomy as her treatment:

> .... I have found that age, marital status, and family enter into every decision about breast cancer. No one can put herself in another woman's place. In my own case, being almost forty-five, with my youngest child reaching sixteen, and being guaranteed an operation with minimal physical after effect, I simply did not want to worry about the inevitable side effects I would have if the axillary nodes were left in and irradiated. Other women may feel differently - and, as far as I can find out, the outcome is pretty much the same after ten years or so. **The important thing is that what I chose was my own decision.** (Kushner, 1975, p.29, *my emphasis*)

A study by Deadman, Dewey, Owens, Leinster and Slade (1989) suggested that the responsibility of decision-making brings with it a cost in terms of increased anxiety at the time of surgery and in the following year. This must be weighted, however, against the increased depression suffered one year post-operatively by those women who were not allowed to choose their treatment. In their study forty-four breast cancer patients were assessed for their psychological well being both before and at three and twelve months post-operatively. The results suggested that type of treatment, control over treatment and concern for appearance are significant predictors of nature of subsequent mood state. They concluded by stating that:

> In summary, these data support the hypothesis that severe threat, such as that suffered by women diagnosed with breast cancer, is predictive of a state of anxiety, while severe loss is predictive of a depressive state... It must be made clear, however, that these data are not indicative of psychological illness, but rather of the balance of mood towards either anxiety or depression (Deadman et al., 1989, p. 681).

Margolis, Goodman, Rubin, and Pojac (1989) studied women with early diagnosis of breast cancer who have been able to choose between two treatments: modified radical mastectomy and breast-conserving treatment of lumpectomy plus radiation therapy. The interviews took place a year or more post treatment. Fifty-two of the women had mastectomy or lumpectomy and eighteen were women with no diagnosis of breast cancer

but who were aware of being at greater than average risk because of family history of developing breast cancer. The patients were divided into four groups. Group 1 (N=20) consisted of those having lumpectomy plus radiotherapy. These were patients who were advised by their physician to have mastectomy but who went against this advice and chose conservative treatment. Group 2 (N=12) consisted of those undergoing lumpectomy plus radiotherapy. They were advised by their physicians to have this treatment, or were presented with it as an option equal to mastectomy in its curative effect. Group 3 (N=22) consisted of the mastectomy patients and group 4 (N=18) was the control group of women without a breast cancer diagnosis but who were aware of their being at high risk of developing the disease.

Concerns about adverse effects on body image as a factor affecting treatment choice were greatest in group 1 patients, less in group 2 and 4 and least in group 3. Similar differences between the groups were found in the investigated concerns about the effects of mastectomy on feeling sexually desirable. It was therefore concluded that the most important psychological factors affecting a woman's choice of lumpectomy plus radiotherapy or mastectomy is the degree of anticipatory concern over adverse effects on her body image, disfigurement, and whether or not it would represent an insult to her sense of femininity. The authors summarised their findings by saying: "It is reasonable to conclude that all women with the diagnosis of early breast cancer should be given an educated choice about the availability of the two treatments to avoid postoperative regrets" (Margolis et al., 1989, p.196).

This study was retrospective in its approach since the women were interviewed a long time (over a year) after the initial diagnosis and treatment. By that time many of the major concerns that the women had when making their choice may have been forgotten, dealt with or 'put aside'. The control group could not be compared to the study group since they could just 'imagine' such a situation of choice.

Levy, Herberman, Lee, Lippman and d'Angelo (1989) reported a study that examined predominantly the idea of choice regarding treatment for early stage breast cancer. Two general groups of patients were compared. The

first group (N=93) were breast cancer patients who were a part of a randomised trial allocating them to either lumpectomy plus radiation or mastectomy. The other group (N=98) were patients who took part in a behavioural study and who were given the possibility of choosing their treatment. Of the latter group, seventy percent elected to have breast conservation therapy. Patients of both groups were assessed three to five days postsurgery and again at three months follow-up, using the Profile of Mood States (POMS), a well-validated mood measure.

The findings showed that in the 'choice' group, the conservation group was psychologically worse off, they were significantly more distressed over time and more depressed in general. By contrast, in the randonised group of patients, reported overall distress decreased over time.

The authors suggested three main conclusions from the data. First, when early-stage breast cancer patients have some choice regarding the extent of surgery, their emotional distress in general increases, at least in the short run (in the case of that study, over a three months follow-up period). Second, coincident with overall higher levels of emotional distress in patients opting for an excisional biopsy is a decrease in emotional support from significant others in these patients' environment. Third, within the context of a randomised treatment trial, emotional distress sequelae increased over time, irrespective of treatment modality. Surgical group differences appeared to be more subtle, with depression increasing over the follow-up period for those assigned to excisional biopsy (Levy et al., 1989).

At the end of their report the authors put forward the question "Now that the woman has a choice, is she better off?" Their answer to that was:

> Given the results of the recent trials, she is not biologically better off, as there appears to be no biological advantage favoring one surgery over the other. Is she cosmetically better off? In some cases she is. But psychologically is she better off? We believe that the verdict is not in. But based on the data reported here, as well as the results reported from the British study [*Fallowfield et al., 1986, my addition*] we may have to question our assumptions in this regard...
>
> In conclusion, we are not suggesting women should not opt for a breast-sparing technique. What we are suggesting is that this is not a

> panacea. Health care professionals should recognise the special needs that may remain in this group of patients. (Levy et al., 1989, p.374).

It will be argued here that the participation of the woman in these choices has an important role in her psychological adaptation to the disease and its treatment. It will further be suggested that appropriate nursing intervention in the form of counselling support can help the woman to successfully negotiate this decision-making process. This will be further elaborated in the next chapter on decision-making. The patient is, therefore, not likely to approach these decisions with cool rationality. Her analysis of the situation is affected by fears concerning her competence to make the correct choice and the anticipated complications in case of a 'wrong' decision. Therefore, it is of note what women actually choose as their treatment when given the opportunity to participate in decision-making concerning the operative strategy.

In a longitudinal study carried out between 1979 and 1987 in Newcastle (Wilson et al., 1988), 153 women who would customarily have been treated by mastectomy were given the option of conservative treatment. Fifty-four chose this option while 99 preferred mastectomy. The mean age, age range, menopausal state, and size of tumour in the two groups were similar. Twenty-eight of the women were interviewed more than two years after they had chosen their treatment. Twenty-four women claimed that it had not been a difficult decision to make since they had been 'motivated' towards one treatment. The rest said it had been difficult and two of these were in retrospect unhappy about having had to choose. Patients who had chosen mastectomy had done so mainly because conservative treatment would last for five to six weeks thus disrupting their domestic or working lives, and because they wanted a quicker solution to the problem, or, they could not live with the uncertainty that they might need a mastectomy later. The results of this research reconfirmed that only **some** women will choose the treatment that will preserve their breast when this is possible. The authors concluded that "Patients with breast cancer are capable of choosing treatment and should play a part in deciding which treatment to have. They do not automatically choose to retain the breast" (Wilson et al., 1988, p. 1169).

The Times in its editorial commented on this study as follows:

> Doctors who believed that given the choice, women would prefer conservative treatment for breast cancer - a lumpectomy rather than a mastectomy were surprised in 1988 when Mr. Ron Wilson, a Newcastle surgeon, reported in the BMJ that twice as many women would rather have the breast off than merely have the tumour excised. Pulse magazine reports that Newcastle surgeons have now studied the reactions of another 220 women with cancer of the breast. Despite detailed explanation and counselling, more than half the women still opted for major surgery, and the surgeons have also noted that those who had the breast off later suffered less anxiety and depression than those who had a lumpectomy. The view expressed by the women seems to have been that they felt that so long as the breast remained there was a greater chance of recurrence, and that this was an added anxiety which they would find intolerable. Mr. Wilson's results suggest that the overriding desire to get rid of the cancer, even at the expense of the breast, is greater than any fear of the loss of femininity. As confidence in the treatment of early tumours by local resection plus examination of auxiliary lymph glands followed by radiotherapy and Tamoxifen, increases in the community, it may be that options will change; but at present it would seem reasonable to acquiesce in the patient's demands, however irrational they might seem to the doctor. (Times, 11th July 1991, p.8)

It appears then, that the choice of treatment is an individual one, and that no way or method is available to the health care team for predicting what treatment a woman will select. Factors that might affect the woman's decision like age, marital status, size of tumour and others, allow no clear prediction of her eventual decision. This conjecture has been contradicted by Owens, Ashcroft, Leinster, and Slade (1987) who found that patients who gave a high rating to concerns about their appearance chose lumpectomy or, if mastectomy was necessary, chose subsequent breast reconstruction. Conversely, those who rated low concerns about their appearance chose mastectomy and did not choose breast reconstruction. From this study it seems that concerns about maintaining an intact body image is an important factor in the decision about treatment, whether the decision is made by the patient or the surgeon. It is also worth noting that in the same study nearly all the interviewed women who chose conservative surgery or reconstruction said they felt that they would have been devastated without these options. Similarly, those who chose

mastectomy, said they felt that they would have been unhappy with just a lumpectomy.

Mastectomy and Lumpectomy - the Different Psychological Consequences

In view of the psychological impact of breast cancer on body image and sexuality, and the fact that the modern treatment for primary breast cancer does not necessarily imply the removal of the breast, the psychological consequences of mastectomy and lumpectomy have been extensively compared. The results of such studies generally indicate that conservative treatment for primary breast cancer does not protect the woman from all the psychological effects. In a summary of the results of such studies that were published up to 1988, comparing the psychological consequence of both treatments for primary breast cancer, Fallowfield (1990) wrote that:

> There are to date ten published studies comparing quality of life in patients treated for breast cancer by mastectomy or breast conserving procedures. Despite the large number of assessment methods employed, one clear finding emerges, which is that there is no improvement in the quality of life following lumpectomy, although a small advantage in terms of body image is seen in five of the studies. The impact that a diagnosis of cancer has on quality of life is not necessarily ameliorated by sparing the woman the trauma of breast loss. (p.100)

This observation is further explained in that:

> The intuitive assumption made by many people that techniques to treat breast cancer, which do not demand extensive mutilating surgery, would result in better quality of life without compromising survival, have not been realised. There are to date no firm data showing an advantage with breast conservation and radiotherapy. There is evidence that mastectomy causes extreme distress and considerable psychiatric morbidity in those women for whom body image is their primary focus of concern, but the majority of women are more concerned about getting rid of their cancer. (Fallowfield, 1990, p.99)

It should be noted that since these observations, seven more studies have been published to further understand the difference in the psychological

impact of both treatments. In the following part of this section studies comparing the psychological consequences of both treatments will be reviewed.

Sanger and Reznikoff (1981) were the first to compare the psychological effects of breast saving procedures with modified radical mastectomy. In their study all of the women who underwent the breast-saving procedure made the choice of treatment themselves. Sixteen of those patients had not known of the alternative treatment before, but were informed about it by their surgeon with whom they could discuss it. Four of them sought a surgeon known to perform the more conservative procedure. None of the women who had modified radical mastectomy had made the choice of treatment herself. They were not aware of alternatives and had accepted the judgment of their surgeon. Furthermore, there was a significant difference in the effects of the two treatments on the patient's body image. Patients subjected to the breast saving procedure were less prone to body dissatisfaction, probably due to the less extensive and less disfiguring result of lumpectomy when compared to modified radical mastectomy. Women in the modified radical mastectomy group reported changes in their satisfaction with their breasts, energy level, health, weight, sleep, arms and hands. Sanger and Reznikoff concluded that the more conservative procedure had a clear psychological advantage for the self image of the patient. In contrast to these results, the investigators found no differences in the general psychological adjustment of the two groups. The authors state that it appears that the two procedures differentially affect feelings of body satisfaction, although the general psychological adjustment may not be greatly affected by the procedure used, provided that the woman is well adjusted prior to surgery.

These observations were supported by Schain, Edwards, Gorrell, de Moss, Lippman, Gerber and Lichter (1983) who obtained similar results in a single randomised study. In their study of thirty-eight patients (20 of whom had mastectomy and 18 of whom had lumpectomy plus radiation), aside from body image concerns, there were no marked psychosocial differences detected between the two groups. They found that those women whose breasts were spared in their treatment revealed a more positive reaction to their nude bodies than did mastectomy patients.

However, in other measures of psychological adaptation or indices of emotional distress, patient self-report did not differ significantly between the two treatment groups. Mood states such as depression and anxiety were virtually the same. They commented that: "It is clear that conservative surgery which preserves an intact breast does not categorically eliminate the psychological distress associated with breast cancer therapy. Neither does conservative surgery and irradiation eliminate physical or functional hardship" (Schain et al., 1983, p. 381).

Steinberg, Juliano and Wise (1985) further pointed out that the differences in psychological outcome between lumpectomy and mastectomy cannot be definitely causally attributed to the type of surgery, but are only associatively linked with it. Their retrospective study of sixty-seven patients also revealed that lumpectomy patients were not less anxious or less depressed, but showed better overall adaptation to their surgery and less functional change than mastectomy patients.

Ashcroft, Leinster and Slade (1985), who found similar results to the previous studies, concluded their report of a study of forty patients by stating that:

> Results so far suggest that the best predictor of good psychological adjustment to breast cancer treatment is to establish, before surgery, the importance to the women of maintaining a complete body image. Treatment, preferably with consultation with the patient herself, can then be adjusted accordingly. Thus, disfigurement can be avoided wherever this is of importance to the psychological well-being of the patient. (p.46)

De Haes, van Oostrom and Welvaart (1986) performed a randomised study, comparing Dutch women who underwent modified radical mastectomy with those who underwent lumpectomy followed by external radiation, in order to re-examine the results of those studies mentioned above. They, also, could find no differences between the two groups with regard to psychological or physical discomfort. The only variable which significantly differed between the two groups was reported body image. There were also no differences found in sexual or psychological functioning or in fear of recurrence or death between the two groups.

Bartelink, van Dam and van Dongen (1985) in a retrospective study also done in the Netherlands, came up with rather different results. They concluded their work on 172 patients by stating that: "Breast conserving therapy appeared in the present study to be far superior to radical mastectomy with regard to body image and cosmetic effect. Although breast conserving therapy is more cumbersome for patients and a larger financial burden for the health care system, the benefits are certainly worth the effort" (p.384). Their study demonstrated, unlike previous studies, the psychological advantage of lumpectomy over mastectomy. Although this study involved a larger number of patients, it was both retrospective and only measured issues related to body image feelings. General psychological adaptation such as related to anxiety and depression was not looked at. Items that the patient had to comment on were feeling self-conscious about appearance, feeling ashamed of the body, feeling sexually inhibited and feeling that the body did not belong to her. These items are clearly not related to general coping and adaptation.

Psychiatric morbidity was further assessed by Fallowfield, Baum and Maguire (1986) in 101 patients treated for early breast cancer. Patients were randomised to have either mastectomy or lumpectomy. Their findings revealed a high incidence of anxiety states or depressive illness in both groups with a slightly higher incidence among patients who underwent lumpectomy followed by radiotherapy. They concluded that mutilating treatment is not more responsible for psychiatric morbidity than conservative therapy and that patients treated by lumpectomy need just as much counselling and support as patients undergoing mastectomy. This study, which was supported by the Cancer Research Campaign, was criticised for its retrospective approach and on its relatively small sample size.

A study done in Canada by Lasry, Margolese, Poisson, Shibata, Fleischer, Lafleur, Legault and Taillefer, reported in 1987, established that patients who had undergone total mastectomy showed higher levels of depression and less satisfaction with their body image than lumpectomy patients. However, partial mastectomy patients did not display any measurable increase in fear of recurrence. The latter was an unexpected result. This

study, again retrospective in its approach, had a larger sample size of 123 patients.

A year later in 1988, Kemeny, Wellisch and Schain came up with results of a randomized prospective study of 52 patients that favoured lumpectomy in terms of psychological adaptation. They concluded by stating that:

> ...women in a prospective randomized group who had breast conserving surgery fared better psychologically in the areas of body-image, feelings of attractiveness, feeling of sexual desirability, and anxiety about cancer recurrence than women with mastectomies. This strengthens the rationale for the use of breast-conserving procedures in the treatment of early breast cancer. (p.1237)

Morris and Royle (1988) conducted a study with thirty patients that followed a prospective approach. Twenty of the patients were given a choice of treatment (seven choosing mastectomy and 13 choosing lumpectomy) and ten patients who were not given a choice and underwent mastectomy (because of a central position of the tumour). They interviewed patients once pre-operatively and three times (at two months intervals) post-operatively. Two control groups of patients with benign breast lumps and patients having other surgical procedures were established. They found that there was a marked difference in psychological adjustment between the two groups of breast cancer patients; those patients offered a choice of surgery and their husbands suffered less anxiety and depression than those not offered a choice. They explain that offering a choice of operation may reduce distress. This is likely as levels of anxiety and depression in the choice group were lower than those commonly reported in the literature. Furthermore, levels of anxiety and depression were lower in those patients who chose mastectomy, compared with those mastectomy patients not given a choice of surgery.

In 1989, Meyer and Aspegren reported a Swedish study of 58 breast cancer patients who underwent mastectomy or lumpectomy plus radiation. Thirty percent of the women reported accentuated mental symptoms compared to their mental state before treatment, with no significant difference between the two treatment groups. Psychiatric state, marital adjustment and fear of cancer recurrence were also similar in the two

groups. However, breast conserving treatment seemed to preserve the woman's female identity and acceptance of body configuration. They concluded by stating that breast conservation does not in itself prevent mental problems after treatment for primary breast cancer.

Similar results were found by Wolberg, Tanner, Ramsaas, Trump and Malec (1987). They carried out a study interviewing 119 women before and after their breast operation. They found that psychological problems associated with breast cancer decreased over time, but that effects persisted for at least sixteen months postoperatively. Few differences were found between the 41 patients who elected breast conserving surgery and the 78 who chose mastectomy. Problems then were not eliminated by operations which saved the breast. In their conclusions they state that:

> Time-limited educational and counseling group may be beneficial to breast cancer patients by providing the opportunity to address adjustment concerns and to learn effective coping. However, the need for intensive psychiatric treatment appears infrequently warranted. (Wolberg et al., 1987, p.1655)

Fallowfield, Hall, Maguire and Baum (1990) reported a study of 269 patients with breast cancer. This is to date the largest study done to compare the psychological implications of both treatments for breast cancer. Their main aim was to repeat the study reported in 1986, while overcoming some of the major criticisms made of the previous study, such as small sample size, randomisation of patients and a retrospective approach. This study, therefore, involved a larger number of patients, employed a prospective method and used consecutive patients outside clinical trial setting.

The method involved self assessment questionnaires and semistructured psychiatric interviews. The self assessment questionnaires that were given to the patients were the Hospital Anxiety and Depression Scale (HAD), the Rotterdam Symptom Checklist and the Spielberger State/Trait Anxiety Inventory. These measurments were made pre-operatively and at two weeks, three and twelve months post-operatively.

The results of this study generally suggest that at two weeks post surgery anxiety was high and declined with time. There was no significant difference at anxiety levels between the two treatments. Anxiety was found to be lowest for patients whose surgeon offered them a choice of treatment. Depression was also lowest in the patients of surgeons who offered them a choice. Depression seemed to decrease with time for patients who had lumpectomy rather than mastectomy. The authors concluded by saying that:

> Fear of cancer and of its possible recurrence seems to be a compelling factor in determining a woman's preference for treatment. The effects of offering women a choice of treatment whenever possible do not seem to be the only variable that might have some impact on psychiatric morbidity; our results suggest that surgeon type and the manner in which decisions on treatment are made may also influence outcome. The women who were treated by surgeons who offered a choice seemed to have less psychiatric morbidity than other surgeons' patients, whether or not they were able to exercise real choice. (Fallowfield et al., 1990, p.579)

In 1992, Lee, Love, Mitchell, Parker, Rubens, Watson, Fentiman and Hayward reported a prospective study of 197 women who were randomised to either mastectomy (n=97) or lumpectomy (n=100) for their breast cancer. In order to assess psychological morbidity they interviewed (in a structured manner) the women before surgery and three and twelve months after.

They found a generally high level of anxiety and depression in the women before surgery. At three and twelve months they observed no difference in new cases, social adjustment and capacity to return to work between the two treatment groups. They also suggested that morbidity relates to stressors common to both groups, particularly that related to having cancer. The only significant difference that was found was in psychosexual adjustment. Mastectomy patients were more likely to have stopped intercourse completely by twelve months.

It should be noted, however, that by the second and third interviews many patients (7% and 12% respectively) have withdrawn from the study for various reasons, including recurrence. This by itself may have provided

bias to the results since these women who withdrew might have been exactly the ones that were distressed and that would have shifted the overall results.

Another recent study was done in Sweden by Omne-Ponten, Holmberg, Burns, Adami and Bergstrom (1992). They conducted a prospective study where they interviewed in a semi-structured way 99 women with breast cancer. The interviews took place four and thirteen months after the operation. At four months they found that women who had radiotherapy or who returned to work had poorer psychological adjustment. At thirteen months the scoring indicated that radiotherapy had a reassuring effect. In general they examined an overall better psychological outcome in the breast conserving group, except for sexual disturbances. In their study, however, they did not monitor the women for their psychological adaptation before the surgery. The initial threat from cancer that may lead to high levels of anxiety and depression in both groups of women may be most profound before the operation. Without this baseline data it is difficult to arrive at any clear conclusions concerning the psychological adaptation to the different surgical treatments.

Pozo, Carver, Noriega, Harris, Robinson, Ketcham, Lagaso, Moffat and Clark (1992) conducted a study to further examine the effect of surgical procedure and choice on adjustment to breast cancer. In order to overcome some of the limitations of previous work, they designed a prospective study of women who chose their treatment. Breast cancer patients were interviewed the day before surgery (in order to have a baseline measurement), ten days after surgery (to have a measurement close to the time postsurgery) and then at three months, six months and one year follow-ups. Patients included 24 women who received mastectomy on strong recommendation, 24 who chose mastectomy for other reasons, and 15 who chose lumpectomy. Subjective well being was assessed in terms of mood disturbance, perceived quality of life, life satisfaction, marital satisfaction, perceptions of social support and self-rated adjustment to their treatment. The results indicated that groups differed in well-being in only one aspect: lumpectomy patients reported a higher quality sex life at six and 12 months postsurgery than mastectomy patients. The choice of

surgical procedure predicted higher levels of life satisfaction at three months.

In the discussion of their paper they raised the question "why is a difference in the overall emotional adjustment between mastectomy and lumpectomy patients, which many people have expected to see, so elusive?" (p.1297). They answered by explaining that: "Although concerns over body image are quite real (and are surely greater for some patients than for others), the greatest concern for most patients is that they have cancer and are trying to survive" (p.1297). It could be argued though, that although the authors aimed at a prospective approach, the general adaptation to breast cancer cannot be concluded at one year postsurgery. A longer follow-up is necessary in order to examine general adaptation to both surgical procedures and arrive at a sound understanding.

Other authors (Levy, Haynes, Lee, McFeeley and Kirkwood, 1992) came up with similar results in their study of 129 breast cancer patients. They assessed patients three to five days following surgery and again at three and 15 months following surgery. In light of their findings they concluded that breast conservation surgery is not a psychosocial panacea.

> Patients whose breasts are spared have psychological symptoms that appear acutely worse in the short run and, in the end, are similar to those of patients who elect to have mastectomies. Therefore, patients choosing lumpectomies are not necessarily psychologically better off than those electing to have mastectomies. Additionally, these patients, particularly younger patients, may require greater social support and potential mental health interventions than they seem to be receiving (p.349)

From a more specific perspective, Mock (1993) examined the concept of body image and self concept. She compared these issues in four groups of women with breast cancer: those treated with mastectomy alone, mastectomy with immediate reconstruction, mastectomy with delayed reconstruction and conservation therapy. A sample of 257 women completed three self-report measures of body image and one of self concept.

Mock's general findings were that mean body image scores in the conservative surgery group was significantly more positive than in either the mastectomy group or in the mastectomy with immediate reconstruction group. No differences in self concept were evident among the four groups. These findings are interesting since they demonstrate that problems in body image are not necessarily related only to the actual loss of a breast, since they are not ameliorated with immediate reconstruction. However, the study had limitations which may have affected the results: the women were assesssed only at one point after their operation between two months and two years postsurgery; data was obtained only through self administered instruments delivered to the women through the mail; the response rate of the women was poor - only 57 percent of the women returned the questionnaires; and, there was no control group of women without breast cancer.

From all the research literature examining the psychological consequences of the two treatments, it appears that the differences in psychological adaptation between women having mastectomy or lumpectomy plus radiation are not as great as might have been predicted. The only significant difference in coping between women choosing either treatment is that lumpectomy appears to have a less devastating impact on self body image and consequently on sexuality. These studies did not address the major issues affecting the decision-making process taken by women with primary breast cancer; the motives, forces, and factors that play a part in a woman's inner world when making such decisions, and the related coping and psychological adaptations to both treatments. The measurements used in these studies were large scale psychological tests such as the Hospital Anxiety and Depression Scale, the Rotterdam Symptom Checklist or the Profile of Mood States. These tests are not sensitive enough to address such delicate issues as psychological adaptation to breast cancer and its treatment, or the decision-making involved. The analysis made use of statistical methods with no clear reference to the individual woman. It is this personal dimension and aspect which is missing when employing such research techniques. Conclusions from these studies may provide valid generalisations when the study is well designed and uses rigorous methods. These findings,

however, provide little meaningful knowledge of the 'life world' of the suffering individual.

Greer (1979) commented that:

> No systematic studies, however carefully conducted, can convey the feelings of individual patients. This is not to deny the importance of such research; indeed, as I have indicated earlier, large scale systematic investigations are urgently required to obtain accurate data about the psychological consequences of cancer. Such information is necessary, but alone is not sufficient for clinicians. In order to provide much needed psychological support for the patient with cancer, the clinician needs to understand, as fully and as deeply as possible, that individual's feelings. (p.176)

Concluding that breast conservation might not necessarily protect the woman from psychological havoc may raise questions at a deeper level such as: what is the major threat that provokes women - the threat of death or the threat of losing a breast? How is it related to family and social support? and, what sort of support may be available from the nurse counsellor. For nursing to provide a caring programme such questions have to be addressed from a qualitative in-depth point of view.

The Effect of the Illness and Treatment on the Partner and Family

The diagnosis of breast cancer affects not only the woman; it is also her whole family system and its equilibrium that may be involved. Moreover, for most women, the nuclear family provides a crucial form of support. Understanding the woman in her familiar environmental context is therefore of great importance and relevance.

Woods, Lewis and Ellison (1989) summarised the literature published at the time regarding the impact of a diagnosis of breast cancer on the whole family. They argued that although extensive research existed on individuals' responses to cancer, there was little knowledge about the impact of cancer on families. They summarised, from the literature, the concerns of families of cancer patients, and concluded that these vary according to the role of the person with the illness in the family, the time

since the diagnosis and the status of the disease. Different members of the family may express different concerns. Consequently, they concluded, families affect the adjustment of the person with cancer. They are important sources of support. Furthermore, family members cope with cancer in different ways. Despite coping in different ways, they may achieve similar adaptive outcomes.

Another review of the literature relating to the whole family's psychological consequences was provided by Northouse, Cracchiolo and Appel (1991). They discuss four main issues, namely, the impact of breast cancer on the husband, the marital dyad, and the children, and issues related to roles and responsibilities. They concluded that studies in this area suggest that the nature of breast cancer and its effect on the family calls for a family-focused nursing care. In order to work effectively with family members, they say, nurses need to make a comprehensive assessment of the family's communication patterns, support, knowledge about the disease process, stress, and the effectiveness of coping behaviours. Nurses and other professionals need to address the individual needs of the spouse and children, as well as the needs of the family as a whole.

> ... breast cancer has an impact on the entire family system. Nurses and other health professionals can play a vital role in helping the family adjust to the psychosocial impact of breast cancer by functioning as educators, support persons, community resource liaisons, and advocates. (Northouse, et al., 1991, p.222)

In the following section the literature reviewed will relate to the effect the diagnosis of breast cancer may have on specific members of the family: predominantly the husbands and daughters.

The Partners of Women with Breast Cancer

Husbands and partners of breast cancer patients have an important role in the emotional care of their wives. Additionally, they may be themselves psychologically affected and distressed by their spouses' diagnosis, illness and treatment. Whatever type of relationship the couple has, it has been established that the partner plays a major role in the woman's adaptation

to, and coping with, the disease. Taking that into account, it is surprising to note the limited research that has addressed the psychological consequences of partners of breast cancer patients. In 1987, Northouse and Swain reported only five studies that addressed the topic of the partners' adjustment to their wives' illness.

The first exclusive study on the partners of breast cancer patients was published by Wellisch, Jamison and Pasnau in 1978. They administered questionnairs to 31 men whose wives or partner had had a mastectomy. The men were recruited through the women who attended meetings of self help groups, or through the American Cancer Society who contacted women who had had a mastectomy operation within the previous five years. Most men reported good overall adjustment but a subgroup remained distressed and reported adverse effects on their relationships with wives or lovers.

The authors state that the data pointed to the importance of the partner's involvement in the decision-making process. This could become, they say, a focal point of primary prevention in terms of potential negative emotional sequelae. Further, they mention that if the partner is distinctly uninvolved, it is important to find out why he chooses to take such a position. Their conclusion was that:

> The study offers initial data toward the notion that in terms of the psychosocial trauma of mastectomy, the man is anything but a detached observer, even if he takes a seemingly distant, uninvolved stance... for the men in this study, the postmastectomy sexual relationship seemed exquisitely responsive to the general state of the relationship before the procedure as well as to the strain of the mastectomy itself." (p.546)

It should be noted that:
1) The data provided was gained only from a set of self administered questionnairs sent to the participant through the post.
2) The recruitment of partners was done through contact with their wives.
3) The respondants were a sample of a specific affluent well educated part of the population and therefore did not represent the overall population.

4) The wives of the respondants had undergone their mastectomies up to 5 years before the study was done, and the reported adjustment of the man at that time may well not represent the real emotional problems the couple faced immediately after the woman's diagnosis and treatment. Furthermore, the psychological adaptation of the man was tested only at one point in time.

All these factors may have created limitations on the interpertations of the data and the overall conclusions of the study. A most important point to remember is that this study was performed before the introduction of lumpectomy as a possible choice for women diagnosed with primary breast cancer.

Another research on the partners of breast cancer patients was done by Maguire (1981). He studied 52 men whose wives had undergone simple mastectomy and radiotherapy, and 40 men whose wives had been treated for benign breast disease. The partners of the patients with benign disease had been selected randomly from a large group so that they matched the women for age, social class, and stage of the cancer.

In this study, the period surrounding surgery was recalled as a time of considerable strain. Forty of the 52 (77%) men whose wives had mastectomy reported that they had experienced moderate or marked degrees of distress in the interval between hospital admission and surgery, opposed to only 14 (35%) of the controls. The levels of distress declined considerably after surgery. Depressive illness was less common. Seventeen (33%) of the mastectomy partners, but only 3 (7%) of the controls, were judged to have symptoms of depression. Maguire (1981) further reported that: "despite these difficulties, all but 2 (4%) men believed that mastectomy and the diagnosis of cancer of the breast had not impaired their marriage in any way (40, 77%); or had even brought them closer together (10, 19%)" (p.494).

Baider, Rizel and Kaplan De-Nour (1986) studied the adjustment of couples to both mastectomy and lumpectomy. They interviewed 32 postmastectomy women and their partners and 32 postlumpectomy women and their partners. The subjects were also administered three

adjustment self reports. The two groups of patients were matched in terms of age, time since operation and postoperative treatment. Whenever possible, matching also included marital condition and levels of education.

Their results revealed that partners in both groups reported somewhat more adjustment problems than their wives. In both groups the men were less satisfied than their wives with the treatment the women received. However, the adjustment of the men of the two groups did not differ. Another interesting finding of Baider et al. (1986) was that the family perception of the postmastectomy women suggested that they felt they had more support within the family than did the postlumpectomy women. This was actually the only item that significantly differed between the two treatment groups. The authors suggested that it could be that postlumpectomy women were high copers and that the attitude of their families was 'now you are well and that's it..', whereas the attitude of the families of the postmastectomy patients was more supportive. Thus, the greater family support in the postmastectomy group somewhat decreased the stressfulness of the situation.

They (Baider et al., 1986) concluded their study by commenting that: "...there is not a major difference in the adjustment of women to breast cancer. Thus, lumpectomy cannot be regarded as a way to cure the postmastectomy adjustment problems of women **and husbands**" (my emphasis, p.256). This study is one of the first to have looked at the men's adjustment to their wives' breast cancer. However, the results are limited since they provide only retrospective data of a relatively small number of couples at one point along the 'breast cancer adjustment continuum'. The results of the self report adjustment tests were analysed and described, but it is not clear in the discussion what data was provided by the actual interviews.

From a different perspective, Northouse and Swain (1987) conducted a study of 50 breast cancer patients and their partners to compare their psychological adjustment at two points in time. Time 1 interviews were conducted approximately three days after surgery; time 2 interviews were conducted 30 days later. Patients and partners were also given standard

questionnaires to measure their psychological adaptation. They found that both patients and partners experienced considerable stress during the hospitalisation period. Many men commented on the stress and exhaustion they experienced. They described difficulties in having to juggle work responsibilities with added home responsibilities while still spending time visiting and offering support to their wives.

The men in that study were not immune to the reverberating effects of the patient's illness, they experienced marked alterations in their moods and increased levels of distress. Comparisons of patients' and partners' psychosocial adjustment 30 days after surgery indicated they did not differ in terms of overall mood states or levels of distress.

Northouse and Swain (1987) concluded their study by suggesting that one of the implications for practice is that:

> ... health care professionals need to direct more attention toward the adjustment of mastectomy patients' husbands... Both mastectomy patients and their husbands have difficulty in adjusting to the impact of the illness and therefore both have legitimate need for support and understanding from nurses and other health professionals. (p.225)

In 1989, Northouse further reported on this same study of 50 breast cancer patients and their partners. She explains that three specific concerns were reported by subjects on the broad area of survival: they were worried about the extent of the cancer, afraid of recurrence, and concerned about a shortened life span. Of these, worry about the extent of the cancer was the most frequently reported concern of patients and partners during the hospital period (time 1). Survival concerns remained most important for the majority of patients and partners one month after surgery (time 2). Within this category, however, patients' and partners' concerns about the extent of the disease decreased by approximately one-half between the hospital and the home period, whereas their concerns about recurrence nearly doubled from time 1 to time 2.

The results of this study indicated that there may be a phase-related pattern to subjects' concerns - with certain concerns being more typical in

one phase of illness than in another. For example, worry about the extent of spread of the disease was a common concern in the hospital but seldom mentioned after patients' return home. On the other hand, fear of recurrence was more commonly reported after patients' discharge home.

This study (Northouse, 1989) was also concerned with the sensitive issue of viewing the mastectomy incision. For the most part, partners reported no difficulty in seeing the incision and communicated their positive, accepting reaction either verbally or nonverbally to their wives. Only a minority of men had difficulty in accepting the result of the operation. For those who did, two indicators of their difficulty in seeing the site were described. These were the tendency to delay seeing the incision, or the use of negative language when describing the incision.

Northouse (1989) stated that:

> The results of this study suggest that the factors that help patients and husbands cope with the breast cancer may change over time or may be more important in one phase of illness than in another. As nurses and other health care professionals gain a better understanding of the changing concerns of patients and spouses over the course of this illness, they will be more effective in designing phase-related strategies that can help patients and husbands cope with the effects of illness. (p.283)

To conclude, an examination of the men's adjustment to their wives' breast cancer has showed that they may find the situation very difficult to cope with. As Baider et al. (1986) pointed out, some of the partners of breast cancer patients presented higher levels of anxiety and stress and were less satisfied than their wives with the treatment results. Partners of both lumpectomy and mastectomy patients may need a great deal of support which is at present still underestimated.

The Daughters of Women with Breast Cancer

Having a first degree relative (mother or sister) who has suffered from breast cancer is one of the highest risk factors for developing the disease (Boyle and Leake, 1988). This medical epidemiological aspect of the illness is well known even to lay people. It is this knowledge that would make

one assume that daughters of breast cancer patients might experience high levels of anxiety about their developing the disease. This anxiety may also affect their breast awareness behaviour such as practicing BSE (Breast Self Examination) and attending mammography screening. Furthermore, the sexual behaviour and the general quality of life of such daughters may also be affected as a consequence of experiencing their mothers illness.

Lichtman, Taylor, Wood, Bluming, Disik and Leibobitz (1984) studied the relationships with children after breast cancer diagnosis. They interviewed 78 breast cancer patients to document perceptions of changes in their relationships with their children following diagnosis. They found that although the majority of mother-child relationships were reported to stay strong or grow stronger following breast cancer, deterioation was evident in 12 percent of the relationships. A most interesting finding was that the mothers' relationship with their daughters were at a significantly greater risk than were the relationships with their sons. Of the patients, 17% reported that their daughters were fearful, withdrawn, hostile or rejecting, while only 8% reported having problems with their sons. Relationships with adolescent and post adolescent daughters seemed to be most vulerable to difficulties. The authors suggested two explanations for this finding. One, obviously, is that daughters are placed at risk by a mother's breast cancer, whereas sons are not. Emotional upset and anger may result when the daughter recognises her own risk. An alternative explanation for the greater frequency of mother-daughter than mother-son problems is that mothers may lean on their daughters more heavily for support, thus creating demands that the daughters are unable to fulfill. This study (Lichtman et al., 1984), however, did not examine the problems of the daughters of breast cancer patients from their own perspective, it was the mothers' views of the relationships.

To date, only a limited number of studies, dealing exclusively with the daughters of breast cancer patients, have been reported in the literature. Wellisch, Gritz, Schain, Wang and Siau (1991) compared sixty daughters of mothers with breast cancer with 60 comparison subjects without a maternal history of breast cancer. These two groups of women were matched for age, educational level and race. The purpose of their study was to systematically assess differences in several areas. These included

knowledge and attitudes about breast cancer, health behaviour, quality of the mother-daughter relationship, the individual's sexuality and body image, and areas of psychological functioning, namely symptomatology and coping behaviours.

In their observation, daughters of breast cancer patients showed significantly less frequent sexual intercourse, lower sexual satisfaction, and greater feelings of vulnerability to breast cancer. No differences between groups were found in psychological symptoms, coping styles, breast self examination practices, mammography practices, health knowledge, or body image ratings. Contrary to expectations, they found that women at risk of breast cancer showed good overall coping with few signs of significant dysfunctions in relation to comparison subjects.

Wellisch et al. (1991) explained some of the limitations of their findings. Although the two study groups were very well matched, they were selected from a specific area (west Los-Angeles) and therefore reflected the demography of that area. The demography of the study subjects, they say, especially their educational levels and relative affluence, may have provided a "buffering effect" from some of the stress patterns described earlier. The study subjects, therefore, may have been different in this regard even from another nonclinical population of daughters who were less educated and affluent. They concluded by suggesting that: "Further studies of daughters of breast cancer patients with more variability in socioeconomic status and with additional racial dimensions are definitely needed" (p.334).

It should be further noted that the method of recruitment of participants in the study also limited the findings. Daughters of breast cancer patients were contacted through a newspaper announcement. This meant that only daughters who wanted to take part in such a study were examined, and that only women reading that specific newspaper were approached.

In this report (Wellisch et al., 1991) they concentrated on the comparison between daughters of women that had breast cancer and a control group of daughters without a maternal history of breast cancer. In their second report they (Wellisch et al., 1992) aimed to identify the characteristics that

are associated with or are predictive of an adverse or less functional psychological adaptation in daughters of breast cancer patients. They analysed the findings of the same study mentioned in the previous report, of 60 daughters of mothers who had breast cancer. Each subject participated in a single structured interview. The interview contained a section of written, self-administered psychological tests and several sections of structured oral questions presented to the subject by the interviewer.

The general finding reported (Wellisch et al., 1992) was that the subjects who were adult at the time of their mother's diagnosis had fewest adjustment problems. Those who were children had moderate adjustment problems, and those who were adolescent (aged 11-20) had the greatest problems in adjustment. The explanation offered was that:

> The adolescent daughter of a breast cancer patient may associate breast development and maturity with illness, body-image trauma, and even death. Thus, the experience of the mother's disease becomes a heightened threat to the daughter's emotional growth, self-esteem, and identity. (p.178)

Another finding was that daughters whose mothers died were more likely to report long-term life plan changes and role changes with their mothers during the mother's illness. In this group of daughters, their lack of emotional resolution may further alter, dominate, or control their life courses. This may take the form of where they live (near/far from mother), their career choices, or even their choice of marriage partner.

The limitations of such findings should be noted. Beyond the limitations discussed concerning the previous report (mainly with regard to the method of subjects' recruitment), the retrospective nature of this study should be remembered. Daughters were invited to talk about their past experiences related to their mother's illness. To date, no prospective study which has followed the daughters of breast cancer patients from the time of their mother's diagnosis is reported in the literature.

It can be therefore tentatively concluded, based on the limited psychosocial research on daughters of breast cancer patients, that they are an extremely vulnerable and psychologically 'at risk' group. As research has

demonstrated, daughters who are young at the time of their mother's diagnosis are in a particularly sensitive situation. These daughters may suffer from psychological problems later in life as a consequence of having a mother with a diagnosis of breast cancer. The main reason for this psychological havoc is the daughters' understanding of their own risk of developing the disease. Furthermore, daughters of mothers who have died of breast cancer seemed to display even more psychological concerns. The mother's diagnosis may affect the daughter's sexual behaviour and breast awareness practices. In extreme cases, the daughter's capability of forming intimate sexual relationships may be affected.

The health care team, and especially those involved in providing psychological support in the form of counselling, should be aware of the special emotional needs of daughters of women with breast cancer. These daughters should preferably be approached not only through their mothers who attend the breast clinics, since the mothers may underestimate the concerns of their daughters. Recognising the psychological requirements for the support of daughters adds another group of vulnerable women affected emotionally by the disease.

Summary

In this chapter the medical treatment of primary breast cancer and the general psychological consequences of the disease were reviewed within the biomedical and psychosocial paradigms. In the first part, the medical treatment of primary breast cancer, which includes primary therapy (surgery and postoperative radiotherapy) and adjuvant therapy (chemotherapy and/or hormonal therapy) was discussed. The discussion concentrated on the change that has characterised the medical treatment of the disease in the last two decades, demonstrating a shift toward a more conservative form of operative treatment. This development was based on medical uncertainty concerning the preferable treatment for early stage breast cancer. It was assumed that preserving the breast provided a psychological advantage for women and saved them the agony related to the loss of a breast. This is where psycho-oncology research had its contribution. In the past, psychologists discussed the issues of the

emotional consequence of mastectomy and the psychological adjustment to its results. However, since the introduction of lumpectomy and methods of breast reconstruction (when mastectomy is necessary), a whole new area of research in psycho-oncology has emerged, which has examined the psychosocial consequences of these different treatment modalities. Furthermore, introducing the woman to both treatment options and enabling her to choose her preferred therapy has also created a new situation of choice which needed to be psychologically evaluated.

The second part of the chapter, therefore, concentrated on relevant psychosocial aspects of the disease. First, the idea of screening women for psychological problems was introduced. Just like medical screening ,which proved able to enhance the effect of treatment, monitoring women for psychological problems may help emotional adjustment. Different mechanisms used for coping with the diagnosis of cancer and its treatment were then discussed. Studies demonstrated that an active response to the diagnosis and treatment of breast cancer, such as in the form of a fighting spirit, may have a positive effect - even in terms of overall survival. Sexual adjustment was then elaborated as a part of general psychological coping and adaptation. In general, the diagnosis of breast cancer and the treatments involved (e.g. the possible loss of a breast) may have a negative effect on body image, feminine identity and consequently on sexuality.

A review of the studies which examined the psychological consequence of the choice between mastectomy and lumpectomy was offered. In general, such studies examined the following areas: factors affecting women in their choice of treatment; what treatments most women actually select; the benefit of being involved in the choice of treatment, and, the various psychological consequences of both treatments. From the existing literature it seems that the threat from cancer is greater than the threat of losing a breast, as a factor in determining the choice of treatment. This may explain the fact that a large number of women still prefer to have a mastectomy as their surgical therapy. They feel that by removing the breast the cancer is also removed, which would guarantee their chance of longer survival. This, of course, contradicts the more modern understanding of cancer as a systemic disease which is spread around the body. Appearance concerns may play a role in determining the choice of treatment only for

those women who regard outer presentation and body image as very important. For these women the possibility of having a lumpectomy, or, a reconstruction of the breast if mastectomy is necessary, is of great advantage.

Studies that have evaluated the psychological benefit of making a choice, have demonstrated that women who participated in the decision-making process regarding their treatment were generally psychologically better off than those who did not take part in such a process. Furthermore, and rather surprisingly, a large number of studies has not been able to prove the psychological advantage of lumpectomy over mastectomy. Research that has compared both treatments has generally shown limited psychological advantage of lumpectomy over mastectomy. The only advantage observed was in terms of feelings toward the body, but no differences were indicated in relation to general mood states of anxiety and depression. In a few of these studies, women who had mastectomy were even found to be coping better than those who had a lumpectomy. This may be explained by the uncertainty concerning lumpectomy as a new treatment method for primary breast cancer, and the consequent radiotherapy which always follows lumpectomy and which some women find very frightening. One of the main conclusions from these studies is that women who have lumpectomy are not necessarily spared the psychological trauma associated with the disease and may need at least as much counselling and support as women who have their breast removed.

The diagnosis of breast cancer affects not only the woman, but also her whole family. In the final part of this chapter, studies which examined the effect that breast cancer has on the family were reviewed. Special reference was given to the most vulnerable members of the family - the husbands and the daughters.

Partners of women treated for breast cancer are facing a very stressful situation. Their reported levels of anxiety and depression were similar to that suffered by their spouses, and in some cases even higher. Some researchers demonstrated that the coping ability of the partners related to the amount of information they received about their wife's illness and to the degree to which they were involved in the decision-making regarding

their wives' treatment. Similarly to their wives, partners of women who had a lumpectomy were not found to be better adjusted than those of women who had a mastectomy. The difficulties faced by partners were partly a result of the additional domestic responsibilities they had to deal with (especially at the time of their wives' hospitalisation) and by the emotional support they were expected to provide their wives. In general, therefore, men need much psychological help and support to adjust to their wives' new situation of having breast cancer, and to help them support their wives throughout the illness.

Daughters of women with breast cancer are a specific psychologically 'at risk' group of women. Their vulnerability is associated with their high risk of developing the disease and with the special emotional demands that are often placed on them by having ill mothers. These daughters, therefore, deserve special attention from the health care team in helping them to cope with the stress and anxieties provoked by their mother's experience of the disease. Daughters who were young at the time of their mother's diagnosis were found to be mostly affected by their mother's illness.

Chapter III:

DECISION-MAKING AND THE WOMAN WITH BREAST CANCER

Introduction

The idea of women being involved in the decision-making regarding their treatment is a relatively newly developed concept in breast cancer care. This concept has been established as a result of general developments in society and the advancement in the medical treatment of the disease, as well as the understanding of the psychosocial consequences of breast cancer. Moreover, decision-making, especially one related to such sensitive issues, is a complex process involving cognitive, behavioural and emotional elements.

In this chapter the concept of women making decisions is discussed from a feminist perspective. Some general theories of decision-making are also introduced, with special reference to health care. Relevant studies that addressed the idea of consumer participation in decision-making regarding treatment are reviewed. Furthermore, a discussion concerning the decision-making specifically in breast cancer care is provided. The chapter concludes with an exploration of the literature of nursing intervention in the decision-making process.

Women and Decision-Making

From a medical perspective, the treatment of primary breast cancer has developed in the last decade - offering women the possibility of preserving their breasts. This development in the medical treatment of the disease has created a situation of decision-making where women are expected, among others, to decide whether to have a mastectomy or a lumpectomy plus radiation as their surgical therapy. The psychosocial consequences created by the diagnosis of breast cancer and the decision-making regarding treatment is well acknowledged and discussed in the professional literature within the normative models of stress and coping, as described in the previous chapter.

It is not only the medical advancement in the treatment of primary breast cancer that has placed women in a situation of decision-making, but also general cultural changes in our society which have contributed to this new

concept in breast cancer care. People's change toward self-expression and emancipation represent the transformation described by Freire (1972) as the change from a **Culture of Silence** to a **Culture of Freedom.**

Freire, in the Pedagogy of the Oppressed (1972) expressed his belief that a change in society will be achieved through education. He took a political standpoint and looked at the oppressed people of this world. These groups are a result of the **Culture of Silence** that has dominated our society. The oppressed and the oppressors conformed to and accepted the situation of oppression. A revolution is needed, said Freire, that would bring liberation through the employment of a new culture - the **Culture of Freedom.** Education of people by an open dialogue is the method by which to bring about such a revolution. This means that both the oppressed and the oppressors will have to develop a new conceptual outlook of their position in this world. Furthermore, he claimed that the real driving force for such a change has to come from within the oppressed group: "Only power that springs from the weakness of the oppressed will be sufficiently strong to free both [the oppressed and the oppressor]" (p.21).

The feminist awareness and women's liberation movements are an example of such a fight against oppression, as analysed by Freire. The treatment of breast cancer, a topic that involves sensitive issues of femininity, sexual identity and body-image, is an area where women can practice self expression and establish emancipation. One method of exercising assertiveness is being actively involved in the decision-making regarding one's own body and fate.

Audre Lorde (1984), an American black lesbian feminist poet argued the position of women as an oppressed group. She used Freire's work in order to examine what has happened to women. She outlined the importance of dialogue between women. This dialogue she referred to as the **Transformation of Silence into Language and Action.** Women who have kept silent must now transform this silence into talk, action and change. She herself provided an example by talking openly of her experience of confronting the diagnosis of breast cancer. In another essay in the same volume she claimed that the change must come from within women

themselves: black, white, heterosexual, homosexual, rich or poor. Lorde (1984) said:

> But our future survival [as women] is predicated upon our ability to relate within equality. As women, we must root out internalized patterns of oppression within ourselves if we are to move beyond the most superficial aspects of social change. Now we must recognize differences among women who are our equals, neither inferior nor superior, and devise ways to use each other's differences to enrich our visions and our joint struggles. (p.122)

In her Cancer Journals, when describing her own experiences confronting breast cancer, Lorde (1980) explained that: "If we are to translate the silence surrounding breast cancer into language and action against this scourge, then the first step is that women with mastectomies must become visible to each other. For silence and invisibility go hand in hand with powerlessness" (p.61). When recounting her own decision-making experience, she wrote: "I think now what was most important was not what I chose to do so much as that I was conscious of being able to choose [my treatment] and having chosen, was empowered from having made a decision, done a strike for myself, moved" (p.33). She decided to have a mastectomy and further made a choice not to wear a prosthesis or have a reconstruction of her breast. She believed that a cosmetic solution would not make her feel 'normal' again, or rather, the same woman she has been before. As she viewed it: "Every woman has a right to define her own desires, make her own choices" (Lorde, 1980, p.65).

As mentioned earlier, Kushner (1975) also stressed, when discussing her decision-making to have a mastectomy as a surgical treatment for her breast cancer, that: "The important thing is that what I chose was **my own decision** (p.29, *my emphasis*).

But how do women make these very difficult decisions?

General Theories of Decision-Making in Health Care

In reality, decision-making is a highly complicated process that is not easy to articulate. It involves arranging and rearranging information into a choice of action. Moreover, decision-making in the fullest sense includes the implementation of the decision. Gelatt (1989) talked about three parts of decision-making: information gathering, analysis, and making a choice.

Information Gathering: The first part is gathering information that relates to the particular issue of concern. There is a whole range of ways in which one might gather this information: reading, talking to doctors or other professionals and talking to patients or lay people.

Analysis: The next step is processing the information, or, in Gelatt's terms "arranging and rearranging". This includes analysing, thinking about, working with, discussing, meditating on, and immersing oneself in the information. Just as there are different ways of gathering information, so there are many different ways of processing it. Effective information processing leads to a clarification and understanding of the range of possible choices and an understanding of the consequences of each choice.

Making a Choice: Finally, the decision maker needs to make a choice. That is, commit himself or herself to some internal or external action that is based on his/her analysis. The fullest choice includes action. In rational decision-making, the choice point is often described in terms of a scale or balance: if evidence points toward a particular option, that is the option to be chosen.

Janis and Mann (1976) described five basic patterns of coping with a realistic challenge, such as the diagnosis of cancer. These patterns form the basis of Janis' and Mann's conflict theory:

> **Unconflicted Adherence** - the decision-maker complacently decides to continue whatever she has been doing, ignoring information about the risk of losses.
>
> **Unconflicted Change** - the decision-maker uncritically adopts whichever new course of action is most salient or most strongly recommended to her.

Defensive Avoidance - the decision-maker evades the conflict by procrastinating, shifting responsibility to someone else or by constructing wishful rationalizations and remaining 'selectively inattentive' to corrective information.

Hypervigilance - the decision-maker searches frantically for a way out of the dilemma and impulsively seizes upon any solution that seems to promise immediate relief, overlooking the full range of consequences of this choice. In its most extreme form, hypervigilance is referred to as 'panic'.

Vigilance - The decision-maker searches painstakingly for relevant information, assimilates it in an unbiased manner, and appraises alternatives before making a choice.

(Janis and Mann, 1976, p. 658)

They explain that the first two patterns, unconflicted adherence and change, occasionally result in saving time, effort, and emotional distress, especially for routine or minor decisions. However, they often lead to defective decision-making when vital choices are to be made. Similarly, defensive avoidance and hypervigilance may occasionally be suitable but generally reduce one's ability to deal with a serious loss. Consequently, they regard these first four patterns of decision-making as defective. The fifth pattern, vigilance, although occasionally maladaptive (if danger is imminent and a split-second response is required) generally leads to decisions that are best adapted to the situation.

The coping patterns are determined by the presence or absence of three conditions: awareness of serious risks associated with the chosen alternative, hope of finding a better alternative, and belief that there is adequate time to search and deliberate before a decision is required. According to Janis and Mann (1976), people will display vigilant attention when they believe that serious risks are associated with the key alternative, a satisfactory solution can be found, and sufficient time for finding that solution is available.

According to this decision-conflict theory, the factors that affect decision-making operate both before and after a commitment has been made. In predicting these factors the conflict model can suggest a number of ways by

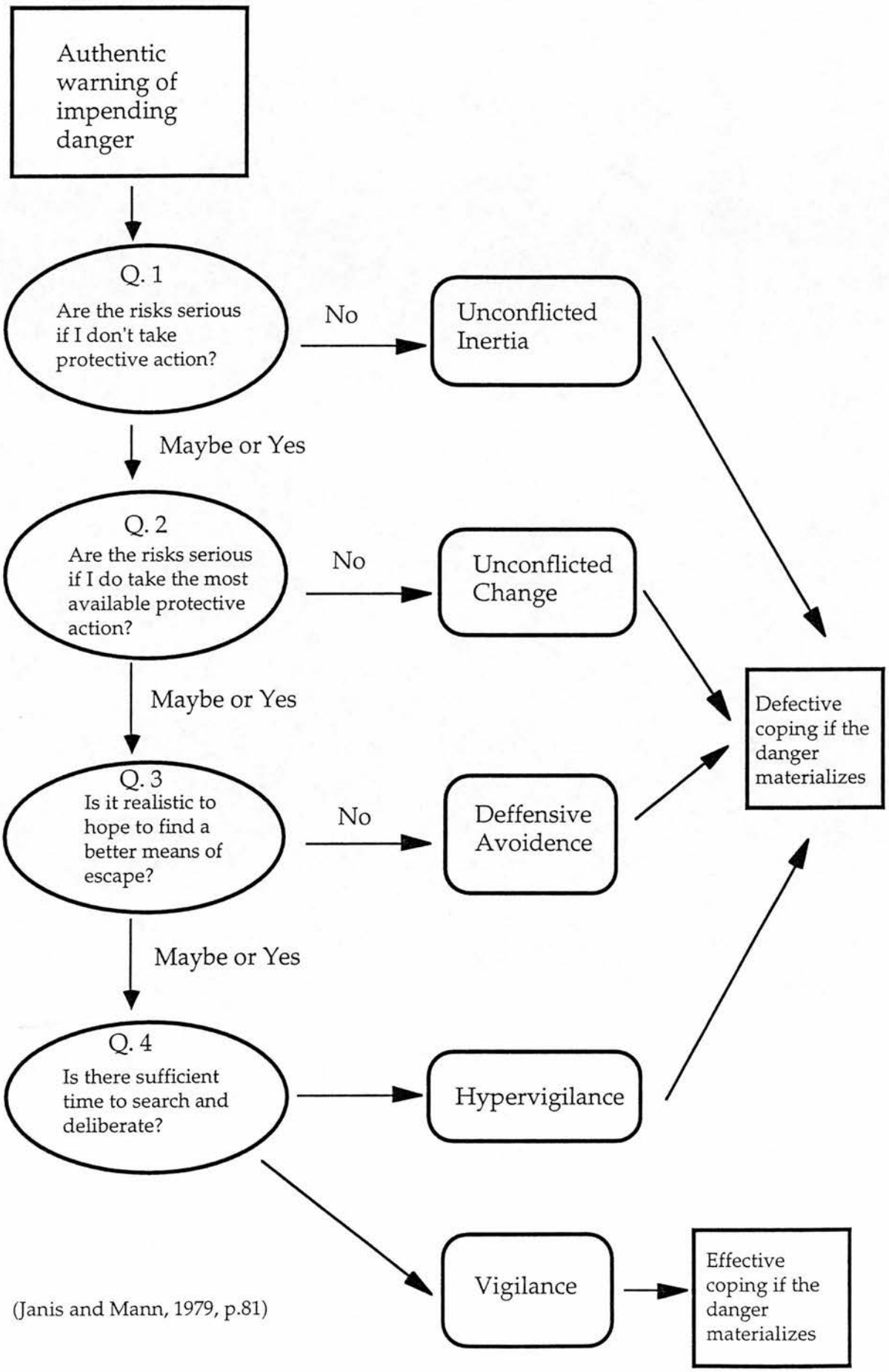
which physicians may help their clients make more vigilant decisions. Guided by decision-conflict theory advisers may be better equipped to counteract unconflicted adherence, unconflicted change, and hypervigilance.

In a later book Janis and Mann (1979) further developed their model of conflict theory analysing basic patterns of emergency decision-making evoked by the warning of impending danger (Figure 1). When a person is confronted with immediate danger the first question he is likely to ask is, 'Are the risks serious if I don't take protective action?' His initial appraisals directed toward answering this question generally take account of the credibility of the communicator of that danger. Is he really informed? Is he telling the truth? If the person accepts the message, he examines signs that show whether or not the predicted threat is likely to affect him. If in his judgement the probability that the threat will materialise is negligible or tolerable his answer to this first question is likely to be negative. In that event, little or no emotional arousal would be evoked by the warning and he would complacently ignore the warning and the accompanying recommendations to take protective action.

As described in figure 1, the next stages depend on the answer to the first question. If a negative answer is given to any of the four questions described, a pattern of coping with the conflict will be defined depending on which question is negatively answered. If a positive answer is given to all the four questions, a vigilant coping pattern is achieved.

At the final stage, if the person believes enough time is available for finding an alternative solution, his vigilance may persist in a much less excited form. Vigilance is likely to be the dominant pattern so long as the endangered person maintains hope of being able to escape and continues to believe that he has sufficient time to find a safe way out. This pattern is characterised by careful search and appraisal, as specified by criteria of vigilant information processing.

Figure 1: Janis and Mann Conflict Theory Model



(Janis and Mann, 1979, p.81)

Gelatt (1989) described his idea of **Positive Uncertainty** in decision-making. He argued that in a decision-making situation, uncertainty may have a positive consequence: it means "...feeling uncertain about the future and feeling positive about the uncertainty" (p.155). Furthermore, he viewed the modern notion of decision-making as removed from the traditional normative models (e.g. Janis and Mann, 1979). As he explained, using this new framework of decision-making is helping someone decide how to move from promoting only rational, linear, systematic strategies to recommending, even teaching intuitive, situational, and sometimes inconsistent methods for solving personal problems or making decisions. "The process of arranging and rearranging, in the mind's eye, is where reflection, imagination, and creativity take place. These are the new decision-making skills for the future" (p.255). Moreover - being uncertain about goals and wants, as described by Gelatt (1989), leads to new discoveries.

Schain (1980) focused her discussion on decision-making in health care. She characterised three alternative types of interaction between physicians and patients in the process of decision-making. Each of them ascribes certain levels of control and power to each party:

> **Activity - Passivity**: an interaction between an active physician and a passive patient. The doctor treats the patient who in turn is regarded as helpless and dependent.
>
> **Guideline - Cooperation**: an interaction between the physician who represents medical authority and the interested patient. This interaction is likely to be operated in health care situations that are not so critical or demanding and so allow a number of alternatives to be considered. In this type of interaction the patient is alert, adult, and capable of rational judgement. However, while this type of interaction allows for dialogue and the patient is given the opportunity to demonstrate intelligent choice, the physician is still viewed as the ultimate authority.
>
> **Mutual Participation of "Shared Responsibility"**: an interaction between a supportive physician and an active patient. This type of interaction is designed to reinforce the qualities of individuality, autonomy, and personal dignity of the patient while preserving a high level of regard for the skills, opinion, and expertise of the physician. According to this concept, the physician helps the patient help himself. In the parlance of transactional analysis this

> behaviour is characterized as an 'adult-adult' communication with one member having the specialized knowledge the other needs. This type of joint participation would not be appropriate for all patients, particularly not for those of very low intelligence and those who are emotionally inhibited from using their rational or cognitive skills to make sound judgement.
>
> (Schain, 1980, p.1037)

She further claims that the last approach of mutual participation and shared responsibility can be used effectively with many more people than is currently permitted, and that patients need to be taught how to achieve such a collaborative status with their health care providers. This approach is gaining popularity especially among social activists, members of humanistic movements, and devotees of self help organisations.

Vertinsky, Thompson, and Uyeno (1974) examined whether patients are motivated by consumer desire for participation in clinical decision-making. They suggested that while consumer participation in design, policy formulation, and even administration of health care is gaining acceptance among professionals, little attention has been paid to decisions concerning clinical procedures. In North America, for example, the patient is viewed as a 'buyer' of information, consultation, and decision services. It is this relationship that typifies most acts of medical care. Physicians make decisions on behalf of patients, presumably choosing the treatment strategies that are 'best' in some sense for the patient. They continued:

> ...differences between physician and patient on the values associated with different courses of medical and preventive actions are to be expected. The physician views the world through a web of medical ethics, professional norms, and a subjective view of the patient's life situation obtained in brief glimpses during the physician's harried schedule of appointments. The consumer-patient views the world through his experiences and may differ in the importance he gives to such concerns as absence of his job, financial sacrifice, or absence from his family. The choice of treatment must be based on resolution of the discordant preference pattern of the physician and the patient. In delegating powers of decision to the professional the patient often, without intending to do so, delegates to the physician the right to define his objectives.
>
> (Vertinsky et al., 1974, p.131)

More recently, Legg England and Evans (1992) reported an Australian study investigating the responses of 143 patients in a cardiovascular risk management clinic to an invitation to make decisions about their treatment. The assumption behind their work was that the outcome of health care will be influenced by the degree of control that the patients feel they have had over the choice of treatment they receive. Health professionals may therefore be able to promote the outcome of health care by encouraging patients to take a more active role in choosing their own treatment. In their study they focused on 1) the nature of patients' treatment choices, 2) variation between patients in the perception of control in the decision-making process, and 3) demographic, cognitive, and health variables that may account for individual differences in these choices and perceptions.

In this study, patients' decisions were largely predictable from prior information: their state of health, the degree of risk posed by their various behaviours, and their motives for coming to the health service. The influence of other people on subjects' choices was also evident. Their choices were related to whether they had been referred to the clinic by another health professional and whether they were allocated to nurse A or nurse B, and many subjects indicated that other people had influenced or swayed their decisions. "Despite the invitation to control the choice of their treatment, there was substantial variation between subjects in how much control they reported they had over the decision" (p.1223).

The authors concluded their report of the study by the statement:

> ...when patients were invited to choose their own treatment, most patients experienced some sense of personal control, while treatment decisions were still substantially influenced by external factors such as assessments of the individual's health risk, and health professionals. Encouraging patients to participate does not guarantee a sense of control in all patients, and practitioners should be sensitive particularly to the effect of the individual's prior beliefs and current health predicament on the amount of personal control perceived by the patient. (p.1224)

I would like to end this section by referring to Egan (1990) who stated that: "...deciding - or letting the world decide for you - is at the heart of living" (p.253).

Decision-Making in Breast Cancer Care

In recent years a shift in the type of communication between the health team and the patient, from an Activity-Passivity form to a Mutual Participation of "Shared Responsibility" (as described by Schain, 1980) appears to characterise breast cancer. This change is related to diverse factors, the primary ones being the general modern trend of consumer participation in decisions related to treatment, women's emancipation, the medical uncertainty concerning the optimal treatment for primary breast cancer and the great psychological impact of the different surgical treatments on the women.

The participation of the patient in decisions concerning her treatment for breast cancer is at least partially based on personal circumstances and psychological needs, and bears importance in her ability to come to terms with the disease. However, she cannot be expected to be qualified for making medically informed decisions. Schain (1980) found that patients rarely have sufficient data for making choices of treatment. In addition, the patient often lacks the necessary guidelines and knowledge for making intelligent inquiries about alternative treatments and on side effects of recommended care. Cynically she commented that women are more demanding and selective of the qualifications of their hairdresser than they are of the person to whom they entrust themselves for health care.

> The medical marketplace is filled with mystery and mythology, and only in the last decade have patients asserted their desire to make choices and insisted on the need for information as a requisite for giving consent to medical treatment. Increasing number of patients are demanding more participation in decisions about their health care, the quality of their survival and the quality of their death. (Schain, 1980, p.1036)

Cassileth, Zupkis, Sutton-Smith and March (1980) have shown that the attitudes of most patients with cancer reflect the wish to be involved in the decisions regarding their treatment. In their study they explored the degree to which patients preferred to become informed with and to participate in their medical care. A total of 256 cancer patients were interviewed to obtain demographic data and information on diagnosis and treatment. Diagnoses given by patients were checked for accuracy against their charts. Additionally, patients completed two questionnaires: an Information Style Questionnaire designed and pretested for the study and the Beck Hopelessness Scale.

They (Cassileth et al., 1980) found that patients' behaviour and beliefs were found to incorporate the contemporary standard of informed and active involvement. Significant age trends were found: the younger the patients, the more closely they conformed to the well-informed participant standard of patient behaviour. The older the patients, the more likely they were to prefer the older nonparticipatory patient role. Patients who wanted to be involved in treatment decisions were significantly more hopeful than others. Moreover, the authors noted that in contrast to the secrecy associated with cancer diagnosis in previous decades, patients tended to inform friends about their specific diagnoses and involve them in treatment decisions. Consistent with the generational trend obtained in this study, younger patients were even more likely to do so.

Different findings were reported by Degner and Sloan (1992). They performed in Canada a study which consisted of two surveys to determine what roles people actually want to assume in selecting cancer treatments. Their sample consisted of 436 newly diagnosed cancer patients and 482 members of the general population. Preferences concerning participation in treatment decisions were elicited using two card sort procedures, each described five potential roles in decision-making. The five roles were:

> A. I prefer to make the final selection about which treatment I will receive.
>
> B. I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.

C. I prefer that my doctor and I share responsibility for deciding which treatment is best for me.

D. I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.

E. I prefer to leave all decisions regarding my treatment to my doctor.

(Degner and Sloan, 1992, 943)

The two striking findings of this study were the high proportion of cancer patients who wanted to leave treatment decisions to their physician, and the marked difference between cancer patients and the public preferences. In light of these findings, the authors suggested that patients newly diagnosed with a serious illness such as cancer are unlikely to seek an active role in selecting their medical treatment, and that the impact of the diagnosis of cancer may influence preferences to participate. They concluded by stating that "...individual assessment of preferences to participate in treatment decision-making remains the best clinical approach" (Degner and Sloan, 1992, p.949). It should be stressed, though, that both the studies of Cassileth et al. (1980) and Degner and Sloan (1992) examined the wish of patients with various cancers to participate in treatment decisions. They did not concentrate primarily on women with primary breast cancer, in which case specific additional factors may influence such preferences.

Even in the media the idea of the patient being involved in decisions over her medical care is being expressed and 'sent over' to the public:

> Not so very long ago, most doctors argued that it caused patients needless anxiety if they were given too much information about their illness. Now they are telling us - surprise, surprise - that women who are allowed to discuss and choose between treatments have lower levels of anxiety and depression later. A study of more than 250 women with breast cancer, reported recently in the British Medical Journal[1] , showed that it wasn't so much the type of surgery that made women depressed but lack of information and the feeling

[1] For a more detailed description of this study see Chapter 2 section on the psychosocial implications of the choice between mastectomy and lumpectomy: Fallowfield, Hall, Maguire and Baum, 1990.

> that they had lost control of the situation. This is not the first study to come up with such findings. How many more do we need to state the obvious? Researchers fear that women who are given a choice and become ill again will blame themselves. Freedom of choice implies taking responsibility for decisions. However, people who don't want that responsibility can always say so right at the beginning. (Observer, editorial, 25th April 1990, p.16)

Deming (1988) suggested that many patients with breast cancer would defectively cope with the imminent danger of the illness and only ineffectively participate in decision-making concerning their therapy. It was further suggested that a large proportion of the patients would in fact prefer to escape the participation in this decision-making process. She wrote that:

> ....we have seen that a sizable percentage of women in our sample were quite uncomfortable with the prospect of electing their form of treatment (23%), while another 24% described themselves as only 'somewhat' comfortable with this option. During interview, many women said they felt it would have been easier if the physician had recommended the best course of action for them, and that in fact they had often tried to elicit such an option from their physician... We find that under the real-life conditions of genuine medical crisis, people may react very differently from how they **say** they would react when questioned on a hypothetical basis... (p.183)

Based on her results, she continues her conclusion by questioning the 'ideal' of giving women the responsibility of making decisions concerning treatment:

> Theoretical studies conducted to ascertain how **much** active participation in medical decisions people desire may tend to overestimate the strength of this desire, especially in individuals who must grapple simultaneously with the shock of a frightening diagnosis, and with a demand to evaluate highly complex medical information under fairly extreme pressures... (Deming, 1988, p.157)

Pierce (1985) wrote a doctoral dissertation entitled: Decision Making of Women with Early Stage Breast Cancer: A Qualitative study of Treatment Choices. In her qualitative research of 48 women who underwent a

decision-making process concerning their treatment for breast cancer, she identified three different frames of choice: the reference, difference and comparison frames.

In an article published in 1993, Pierce provided further analysis and interpretation of the decision-making behaviour. She described three styles of decision-makers: deferrers, delayers and deliberators.

> **Deferrer**: subjects in the Deferrer decision-group (41%) appeared to be influenced by the silience of a particular alternative, which allowed them to make quick, conflict-free decisions. They frequently selected the alternative recommended by the physician, deferring to his or her expert judgement...
>
> **Delayer**: Delayers (44%) appeared to structure the decision problem in a way that allowed consideration of, and hence deliberation about, at least two options... Their deliberation was random and superficial, and they appeared to jump from the consideration of one option to another...
>
> **Deliberator**: Deliberators (15%) expressed a personal responsibility for making a quality decision and took charge in a manner that was more deliberative and purposeful than those of the previous decision styles. These subjects are distinguished by four characteristics: (a) the use of a strategy of plan, (b) an explicit consideration of risk, (c) expressed confidence in the decision-making process, and (d) a lingering uncertainty about the eventual outcome and anticipation that at some time in the future they might regret their choice... (p.25)

The findings of this study revealed that deferrers were older than subjects in the other groups. Deferrers reported satisfaction with their choice and did not anticipate future reconsideration or regret. The delayers were younger than deferrers. They also avoided the consideration of risk. If they sought information at all, it tended to be of the popular variety. Deliberators, however, unlike deferrers and delayers, experienced lingering uncertainty and anticipated regret. Additionally, many of them denied that there was a best choice. They were the minority of the patients in that study and the youngest group.

The author suggested that of the three, the style of the deliberators is closest to normative models of decision-making (e.g. what Janis and Mann

defined as Vigilance) because of how the decision problem is represented. It is worth noting, she added, that "...the subjects in this group experienced the greatest psychological distress and required the most resources of time, energy, expert opinion, and information to make decisions "(p.27).

Information seems to be an important element when presenting patients with the possibility of deciding on their treatment. Concerning the participation in medical trials, for example, a research done by Sheldon, Fetting and Siminoff (1993) demonstrated that cancer patients' routine overestimation of their prognoses with standard therapy may inhibit their accrual to randomised clinical trials, for which standard therapies are the alternative. They stated that "Patients' appreciation of the rationale for a trial, and the potential benefit of trial participation, can only be enhanced if they understand their prognoses with standard therapy" (p.62).

In this study, 282 ambulatory breast cancer patients were randomised to receive either one of two forms of a written information sheet on adjuvant chemotherapy treatment. This information sheet described a hypothetical premenopausal patient with two positive axillary lymph nodes considering a choice between CMF and clinical trial comparing CMF and CAF. One form numerically described results with standard CMF in terms of 10-year disease-free survival, whereas the other verbally described outcomes with CMF in less specific, qualitative terms. After considering the information, patients indicated their choice between CMF and the trial, as well as their estimates of 10-year disease-free survival with CMF. Their (Sheldon et al., 1993) interesting finding was that patients who overestimated the benefit of standard CMF were significantly less likely to select the trial. In the light of these results, they argued that clinicians should provide patients with accurate information concerning diagnosis and prognosis, especially when inviting them to participate in medical trials:

> However, clinical investigators may be reluctant to provide specific information that deflates patients' estimates of their prognoses. The routine withholding of information regarding the modest benefits of standard therapies may avoid patients' distress, but such physician behavior is paternalistic and may deleteriously affect trial accrual. (p.62)

The results of the above study may be criticised on the grounds of the basic assumptions the researchers made and on methodological aspects. However, the idea of the importance of the quantity as well as quality of information given to patients who are invited to decide whether they would opt for standard therapy or join a randomised medical trial evaluating alternative therapy, is worth paying attention to. The way the information is presented to the patient may clearly affect treatment decision-making.

To conclude the idea of decision-making, it is important to note that the choices involved in breast cancer care are many, and continue throughout the course of the illness. They begin when a woman decides whether to go for preventive screening, or whether to see a doctor if she finds a lump in her breast. Consequently, she may be confronted with the various treatment options if cancer is diagnosed. The patient meets with the need to choose between different treatment options at different levels. In cases of early tumour development, she may be asked to decide on the primary treatment - mastectomy or lumpectomy with consequent radiation therapy. But, she might also be facing other crucial choices. Whether or not to enter a clinical trial for her treatment and whether or when to have a reconstruction of the breast (if mastectomy was chosen), are but two examples. There is little mention of this level of decision in the literature.

One clear implication from the works of, for example, Pierce (1985, 1993) and Deming (1988) is that women with early breast cancer should be evaluated as to the level of stress they are experiencing, as well as to their attitudes toward the option of choosing their treatment. For the more anxious women and for women who generally feel less comfortable about exercising this option, it would be helpful if the nursing staff could provide them with active and initiated support and structure that would enable them to participate in determining the course of their treatment.

Denton (1988), a senior nurse counsellor in breast cancer care, summarised by stating that:

> Always the nurse should consider whether opportunity for discussion of treatment, or treatment options, has been given and whether the patient has consented to the treatment whilst being

fully informed. Without knowledge and guidance from professionals, patients cannot make decisions about treatment. (p.102)

Nursing Intervention in the Decision-Making Process

Since patients carry the major responsibility for their own health, they have the right to participate in decisions on treatment that affect their health. As patient advocates, nurses have an ethical obligation to see that those rights are respected. Nurses have a primary responsibility to inform the patient about proposed nursing care and they must obtain the patient's consent, usually through the patient's verbal permission or informed cooperation (Nurse to Nurse, 1987). Furthermore, nurses have a responsibility to assess the patient's knowledge of the proposed medical treatment and to give additional clarification on the treatment if necessary. The purpose of these actions is to enable patients to exercise the **right of choice** in deciding what will be done to their bodies. The nursing literature suggests that breast cancer care has many of the elements required for exercising this right.

Valanis and Rumpler (1985) were among the first to address the practical way in which nurses can help women to choose breast cancer treatment alternatives. They suggested a summary of the intervention strategies for facilitating decision-making in women suffering from breast cancer. At each point on Table 1, along the breast cancer health care continuum, there is room and need for specific nursing intervention:

Table 1: Valanis and Rumpler's Intervention strategies for Facilitating Decision-Making in Women at Risk for Breast Cancer

Phase of health care	Technique of intervention
Prediagnosis	Media presentation of breast cancer General education about breast cancer Programs in educational institutions and social/occupational settings Health assessment and individual counselling of high-risk women
Diagnosis	Nonjudgmental provision of facts Patient participation in deciding treatment alternatives Family involvement in decision-making
Treatment	Two step surgical procedure Individual counselling

Adapted from Valanis and Rumpler, 1985, p.173

Another practical tool that can assist nurses in helping women who are faced with a decision-making situation is the **Informal Decision Analysis** (IDA) model, suggested by Owens et al. (1987). When, for example, the choice of mastectomy or lumpectomy is offered, the woman is asked which treatment she would like to discuss first. After making that choice, she is asked to list all the events that might occur as a consequence of that treatment. Having formulated this list, she is asked to give her own assessment of the chance that each event will happen. The woman is further asked to assess the desirability of each event. Given this information, it is then possible to construct a decision tree and to conclude the subjective expected utility of the treatment the woman has chosen. Clearly, the treatment with the highest subjective utility would be the rational choice.

The major value of the IDA appears to be that it provides women with a framework with which to review the issues of significant importance to them in a systematic way. By assigning values to probabilities and utilities, women are able to see directly to what extent likely and unlikely events

enter into their decisions and the relative importance of various outcomes. Moreover, by breaking the decision into its component parts, they are able to identify what additional information they may require. By taking the issues one at a time, the woman is often able to consider them more calmly and rationally without being overwhelmed by the problem as a whole. This model can help nurses provide women with a practical tool for managing the decision-making process concerning treatments.

Recently, Neufeld, Degner and Dick (1993) suggested a simple and straight forward intervention strategy designed to foster patients' involvement in treatment decisions. The strategy was based on determining the degree of involvement the patient desires (see Degner and Sloan, 1992). The emphasis was on patient's agenda, including assessing to what extent she wants to participate, helping her to identify questions, and supporting her in obtaining the information she wants and needs. Their (Neufeld et al., 1993) strategy was tested on women with a confirmed diagnosis of breast or gynecological cancer. The main idea of this support scheme was that of a specially trained nurse who followed the woman throughout the initial phase of diagnosis, and the decision-making situation. This project demonstrated that a nursing role that provides decisional support can be integrated into a busy oncology clinic. However, the impact of the intervention on outcomes of quality of like, such as anxiety and depression, has not yet been published.

A more general practical concept of nursing intervention was provided by Kendall (1992). She, basing many of her arguments on Freire's Pedagogy of the Oppressed (1972), developed the idea of **Emancipatory Nursing Actions**. She called for nurses to broaden their conceptualisation of environment in order to seek further understanding of the social, political, and economic structure of health, illness and policy. Kendall (1992) said: "In order to conceptualize the role of emancipation in nursing practice, one needs to clearly understand the important aspects of oppression and emancipation" (p.50). She further described:

> Emancipatory nursing actions are those actions that increase the potential for oppressed groups to take power from those who oppress them... [it includes] ...taking gender, race, and class considerations seriously; conceiving all social structures as containing an interplay of contradictory forces that require dialogic

critique in order to understand social reality; unmasking the reifications of everyday life..." (p.9)

Again, like Freire (1972) and Lorde (1984), Kendall argued that the most important factor in emancipatory nursing is the commitment to using communication in as free, undistorted and non authoritarian ways as possible. This she also related to the situation of decision-making. Empowerment is her key word. Using such an approach in nursing will enable women to gain power for making their own choices.

Conclusion

To conclude, changes are occuring in the present health care practice towards a holistic, more comprehensive, medical care. Capra (1983) and Ferguson (1982) examined a general shift in a paradigm of thought in our society, where the practice of health care provided an example of such a development. Ferguson, in the Aquarian Conspiracy (1982) argued that a new paradigm of health will involve a more autonomous patient and a relationship of partnership between the patient and the professional. This is in contrast to the dependancy/authority relationship that characterised traditional health care. Patients' involvement in treatment decision-making is a clear implication of this transformation of thought.

In the current breast care practice, therefore, we meet women who are apparently assertive, demanding of information and willing to make decisions regarding their own treatment. On the other hand, contrary to what we might expect, it may create a situation of confusion, uncertainty, dependency and loss of control on the part of the woman. It may be therefore questioned whether this leads to a growing urge in women for counselling and support from the health care professionals. Is it there where **Emancipatory Nursing Actions** as described by Kendall (1992) can take place? Can counselling and support be seen as a form of Emancipatory Nursing Actions? Will practising such an intervention enable women to free themselves from being the oppressed, and gain power and control in the extreme case of breast cancer? These are just a few of the areas that will be further looked at and discussed in the present work.

Chapter IV:

COUNSELLING IN THE AREA OF BREAST CANCER

Introduction

As a result of the developments in the treatment of primary breast cancer and the acknowledgement of its psychological consequences, the idea of a specialist nurse counselling service has become increasingly common. In the UK, the need of women with breast cancer for further psychological and emotional support was firstly recognised and mentioned in the literature in the late 1970's (Baum and Jones, 1979). Since then, a growing number of nurses have been appointed as specialist breast care nurse counsellors, and the literature has addressed and examined many aspects of their work.

In the following chapter the literature on counselling in breast cancer care will be reviewed. General definitions of counselling are given, followed by a specific discussion of counselling in cancer care. Further, training in oncology counselling will be described and elaborated. The chapter will conclude with a review of the studies that examined the efficacy of oncology counselling. It should be mentioned that, although the discussion in this chapter concentrates on oncology counselling in general, special referance and attention is being made to counselling in breast cancer care. Moreover, the specific focus is on a specialised nurse counselling service.

General Definitions of Counselling

Counselling - A systematic guidance offered by social workers, doctors, etc., in which a person's problems are discussed and advice is given (Collins English Dictionary).

Patient Counselling - is helping the patient to cope with his condition and the treatment involved (Stewart, 1987).

Counselling theories and approaches are extensive. It is beyond the scope of this thesis to review all these various methods of psychotherapeutic helping. Egan (1990) argued that in the face of all this diversity of

approaches to counselling, helpers, especially beginning helpers, need a practical, working model of helping that enables them to learn:

- what to do to help people facing problems in living,
- how to help clients develop unused resources and opportunities,
- what specific stages and steps make up the helping process,
- what techniques aid the process,
- what communication skills are needed to interact with clients,
- how these skills and techniques can be acquired,
- what clients need to do to collaborate in the helping process and to manage their problems and develop their opportunities more effectively, and
- how to evaluate their efforts (p.14).

One of the main approaches to counselling was developed by Rogers (1965, 1967). The philosophy behind his work was that therapy should be concentrated on the person him or herself. He called his theory The Client Centred Approach. Rogers believed that the real healing power comes from within the person and that everyone of us has the inner strengths and resources to overcome and solve our own problems. The only thing which is needed in counselling is facilitation that would enable these inner, at times hidden, resources to come out and act therapeutically. Indeed, **facilitation** is the best word to describe Rogerian counselling. It is with this in mind that Rogers developed his understanding of counselling. Within this framework, decisions are therefore not taken by the counsellor on behalf of the person, and advice as such is not given. The counsellor facilitates the person to arrive at his or her own decision at his or her own time and pace. Solutions to problems are not provided by the counsellor who instead encourages the person to find his or her own solution from an inner personal understanding and insight. This approach has gained much popularity in recent years and has developed into a school of thought called 'Rogerian Counselling'.

Rogers (1967) defined what he called the helping relationship as: "... a relationship in which at least one of the parties has the intent of promoting the growth, development, maturity, improved functioning, improved coping with life of the other" (p.40). As a part of his theory, Rogers (1965) explained that talking with people about their feelings requires three basic attitudes in the counsellor:

Empathy: The ability to sense the other person's world of felt meanings as if they were your own, but without ever losing the 'as if' quality; the ability to step into the other person's shoes for long enough to sense what life is like for him or her. Empathy is very different from sympathy, as sympathy more closely resembles pity or compassion. Empathy involves a greater risk that we might be changed by our experience.

Unconditional Positive Regard: a positive, warm, accepting response to the other person, regardless of how difficult his or her behaviour may be at the moment; the assumption that behind the difficult behaviour is a feeling and almost certainly a suffering person; a respect and liking for the other person. With very difficult people, it may be essential to work hard at finding something one can like in the other person, and ally oneself with that.

Openness to Feelings: Communicating to the other person that whatever the feeling is, we can reply to that and deal with that. Any feeling can be talked about. Some feelings are very painful and we may be motivated to avoid discussing them. However, we will make an effort not to avoid them with the other person if possible.

He continued his argument by saying that there is a substantial nonverbal component to the communication of empathy, unconditional positive regard, and openness to feelings. People can usually tell whether we seem to be empathetic, whether we like them or not, and whether certain feelings can be discussed with us.

Client Centered Therapy, therefore, holds the assumption that people are essentially 'good' and able to make their own decisions. The client-centered counsellor will be listening to the client with this point of view in mind. Moreover, it is the relationship between the client and the therapist that provides the resources for self exploration. As Rogers described his own personal change throughout his professional years: "[in the past] I was asking the question, How can I treat, or cure, or change this person? Now I would phrase the question in this way: How can I provide a relationship which this person may use for his own personal growth?" (Rogers, 1967. p.32).

Gelatt (1989) discussed specifically the idea of counselling in the situation of decision-making. In the previous chapter his idea of a new framework of decision-making was mentioned. This new framework is somewhat removed from the traditional normative models of decision-making and relies much more on intuition, reflection and an understanding that uncertainty in decision-making can actually be valued positively. He further elaborated his idea of decision-making counselling. Gelatt (1989) argued that a new counselling framework must help the client avoid the most common problem caused by old decision theory: pretending one already knows what one wants. "It is not so much a question of should one really know what one wants, but should one be encouraged to develop new wants..." (p. 254) Furthermore, "The main purpose of counselling has always been to help people make up their minds. Now counsellors can add helping people keep their minds open and even teaching them how to change their minds. The best final decision may actually be a definite maybe" (p.255). Decision-making counselling, as viewed by Gelatt, is therefore not necessarily helping the client to arrive at a 'right' or 'wrong' decision, but rather opening the mind of the client to the possibility of uncertainty. This uncertainty should be regarded as a positive step in the process of making a choice.

Some authors examined the idea of counselling as a part of nursing practice. Egan proposed a three-stage developmental model of counselling coupled to specific counselling skills and an optimised temporal plan/or treatment sequence. This theory (as described by Model (1987); Table 2) bears resemblance to the developmental stages of the nursing process.

Table 2: Egan's Developmental Model of Counselling:

Stage 1	Skill	Nursing Process
Exploring	Empathy	Assessment
	Respect	
	Concreteness	
	Genuineness	
Stage 2		
Understanding	Advanced empathy	Planning
	Self-disclosure	
	Immediacy	
	Confrontation	
	Alternative frames of reference	
Stage 3		
Action	Facilitation of action	Implementation
	Plans	Evaluation
	Support	
	Evaluation	

(Adapted from Model, 1987, p.801)

Stewart (1987) also discussed the concept of nurse counselling. Like Egan, he put side by side the nursing process and a counselling model, and showed their resemblance.

Table 3: Stewart's Comparison of the Counselling Model and the Nursing Process

Stage	Counselling Model	Nursing Process
1	Meeting the Client	Assessment
2	Identify the Problem	Planning Care
3	Explore the Problem	" "
4	Action Plan	Deliver Care
5	Implement the Plan	" "
6	Evaluation	Evaluation

(Stewart, 1987, p.29)

Further, he explained that the nurse establishes and maintains her professional relationship with patients on the foundation of trust, respect, understanding and interest. These, he said, are precisely the ingredients of the counselling relationship. The personality of the nurse employed in

counselling and the feelings and caring she expresses are vital to the foundation of the relationship. If nurse counsellors become mechanical in their service, it could be argued that they are not ministering life to the people they service. "Progress and recovery may be seriously retarded by lifeless service" (Stewart, 1987, p.30).

Burnard (1991) proposed a list of minimal counselling skills for nurses which are easily taught and used:
- Listening and attending
- Using open questions
- Reflecting on content and feelings
- Summarising
- Checking for understanding

He pointed out that it is not suggested that the person who has such minimal skills is either equipped or trained to practice counselling. The person who has minimal skills is, therefore, neither a counsellor nor a psychotherapist. However, there are the minimum skills that a nurse or other caring individuals need to have in order to help another person to talk about his or her problems in a therapeutic way.

Burnard (1991) summarised his idea of nurse counselling by saying that: "Although nursing is changing and developing, the need for us to listen and hear what people are saying remains constant. The fact is unlikely to change, however much nursing changes" (p.39).

It may be concluded, that the nurse counsellor does not attempt to give advice but, with empathy and a non-critical judgement of the patient's fears and anxiety, helps to achieve a process of psychological self-healing, to speed up the natural coping mechanisms enabling the patient to come to terms with the disease, its treatment and the consequence of such treatment (Baum and Jones, 1979).

Counselling in Cancer Care

The number of psychotherapeutic and counselling approaches to the cancer patient has grown enormously in the last years (Burton, 1991). There is now an extensive literature on individual counselling and psychotherapy techniques with cancer patients (for example Baum and Jones, 1979; Collins, 1987; Fallowfield, 1988; Maguire and Faulkner, 1988; Buckman, 1989; Davis and Fallowfield, 1991). When group, family, marital, psychosexual and behavioural approaches are considered, the range of techniques widens further. Some of the interventions described in the literature have been provided by health care staff with specialised training in psychotherapy, but elements of these counselling techniques can also be taught to medical and nursing staff in hospital and community settings (Burton, 1991).

Anderson (1988) pointed out that communication with cancer patients is the key role of the nurse counsellor, which is described as being:

> ....to enhance, by thoughtful, planned action, the inherent ability of the patient to cope, and to identify those at risk. There is no magic formula, no set test that will resolve the difficulties. Nursing is, above all, about social interaction, and that requires communication. (Anderson, 1988, p.44)

Six principles for supporting the cancer patient have been suggested by Klein (1971):

> Help her to express her feelings: Nonjudgementally allow her to talk about it.
>
> Help her to sort out the real from the unreal, contradicting views such as that cancer always recurs or kills, that she will be perceived by others as 'untouchable' or that she is somewhat responsible for her cancer.
>
> Don't give false reassurances: 'Don't worry, everything will be all right' is not a helpful intervention. It may not be all right at all for this patient in the future.
>
> Help her to anticipate the future: the depression she will feel for the next few months is part of the normal grieving process.

Help the family to understand the patient's feelings and to express theirs.

Help the patient to consider how and what to tell those significant persons in her life.
(p.1662)

Maguire, Tait, Brooke and Sellwood (1980a) developed a scheme for psychological monitoring of breast cancer patients by nurses. The scheme had the following aims:

- To provide each patient with information, advice and practical and emotional support from the time of admission until 12 months after surgery,

- To help each patient regain full use of the affected arm or adapt to any residual disability.

- To encourage early return to housework, work, social and leisure activities.

- To encourage early resumption of marital or other key relationships.

- To help each woman adapt to the diagnosis, breast loss and other treatments.

- To monitor routinely the physical, social and psychological adjustment of each patient; and when problems were detected which the nurse could not resolve, to refer the patient to an appropriate agency. (p.35)

This scheme, which indirectly described the role of the nurse counsellor in breast cancer care, was further developed and evaluated.

Fallowfield (1988), more specifically, defined five counselling techniques that are used in cancer care:

Informative Counselling - Providing information, giving help with decision-making, and helping understanding.

Directive Counselling - The counsellor acts prescriptively, directing the behaviour of the patient wanting help.

Confrontational Counselling - Challenging unhelpful thinking or coping strategies that are hindering the patient coming to terms with the problem and providing feedback to enable patients to adapt and recognise negative thinking themselves.

Catalytic Counselling - Being reflective and encouraging patients to establish their own achievable goals, thus promoting a sense of control.

Supportive Counselling - Providing acceptance, having empathy and showing genuine concern for the patient and his or her fears and needs.

(Adapted from Fallowfield, 1988, p.727)

She explained that most counselling models contain elements of all the components listed above, and warned against 'untrained' and 'unskilled' counsellors who tend to use too much directive counselling and sometimes double dangerously with confrontation and catharsis.

Wilkinson (1991, 1992) conducted a study exploring general communication skills of nurses employed in cancer care. In her study she aimed at identifying:
1) the extent to which nurses use facilitating and blocking behaviours when communicating with cancer patients;
2) whether there is a relationship between the extent to which nurses use facilitating and blocking verbal behaviours and their levels of social support and work environment;
3) whether nurses are aware that the verbal behaviours they use are blocking or facilitating;
4) nurses' views and feelings about communicating with cancer patients.

The method of the study involved the collection of data from various sources: a) a self-administered questionnaire which included demographic data, fear of death scale, a social support questionnaire and the State Trait Anxiety inventory; b) a tape recorded nursing history with newly diagnosed cancer patient, a patient admitted with recurrence and a patient admitted for palliative care; and c) a semi-structured tape-recorded interview on the difficulties in caring for patients with cancer. The study

was conducted in a specialist and non-specialist hospital. Fifty-four registered nurses completed the questionnaires, audio-taped histories and a semi-structured audio-taped interview.

In her analysis of the data, Wilkinson (1991) identified four styles of nurse-communicators:

Facilitators: Nurses who demonstrated that they were able to use facilitating verbal behaviours with patients at all stages of their disease and were able to achieve a more in-depth assessment of patients' problems.

Ignorers: Nurses who ignored patient' cues and switched topics throughout the interview. This enabled them to keep out of the emotionally loaded areas.

Informers: Nurses who used predominantly inappropriate information and opinion-giving throughout their nursing histories which invariably concerned physical areas of care of procedure to be carried out.

Mixers: Nurses who had no specific strategy for blocking. They used a mixture of facilitative and blocking verbal behaviours and appeared to be genuinely trying to assess the patient's problems and were usually more aware of the blocking verbal behaviours they were using than the informers and ignorers were.

The results of this study presented an overall poor level of facilitative communication. Special difficulty was noted in communication with patients who had recurrence. Wilkinson (1991) suggested that the way nurses communicate may depend on the environment created by the ward sister, the nurses' religious beliefs and attitudes to death, rather than specific education in communication skills.

On the basis of her results, she argued that: "Since those nurses who had completed post-basic training in communication skills were no more effective in communicating than those who had not, it appeared that effective communication does not just depend on the acquisition of skills required to communicate" (Wilkinson, 1991, p.688).

In a later report, however, she (Wilkinson, 1992) still stressed the need for further development and training in cancer nursing:

> The ability to communicate well with patients is more complex than focusing on verbal and non-verbal skills. Nurses need a good knowledge of cancer and treatment options, as such knowledge would seem to increase confidence; they need to explore their own and others' attitudes to cancer and death and they need to learn communication skills and be able to practice them with supervision. (p.28)

Recently, a trend has begun to emerge toward employing specially trained nurse counsellors in breast care (Watson, 1983). The specialist nurse counsellor for breast cancer patients may observe a vast range of reactions to this disease. The woman's emotions often change with the passage of time; commonly, however, it eventually results in the development of a way of coping that is comfortable to her. This natural sequence leading to effective coping may require professional help, but help which should ideally be adapted to the changing needs of the patients. This latter point is of great importance: the patient should always feel she is in control of what is happening to her and thus pace the service offered. A specialist breast care nurse counsellor wrote:

> As a nurse counsellor helping to care for the patient with breast cancer, I see my objective as providing a service which may offer emotional and practical support, assisting the patient to achieve her optimum potential for physical and psychological rehabilitation. With sufficient tact and a modicum of skill a relationship may rapidly be established between the patient and the nurse, enabling her to express her doubts and fears and to explore possible solutions to her problems... It is also of prime importance that the nurse be able to recognize when to terminate regular contact with the patient when the patient's own strategies for coping have become sufficiently well developed. To perpetuate professional contact on a regular basis prevents the patient from feeling she is able to cope on her own, thus singling her out as 'unwell'. At the same time it is advisable to leave some line of contact intact, such as an invitation to telephone. It is assumed that prior to this break a good enough relationship would have been established between the patient and the nurse to enable the patient to feel at liberty to contact the nurse if necessary. (Denton, 1988, p.96)

It can be summarised, that the majority of women might have sufficient natural resources to come to terms with breast cancer when they are supported by nurse counsellors with **specialised training**. It is, however, important that counselling should not officiously interfere with natural coping mechanisms, but should be offered when appropriate.

Training in Oncology Counselling

Maguire et al. (1980a) were the first to address the issue of training in oncology counselling in the UK. They described training which is required by nurses in order to establish their role in a monitoring scheme for breast cancer patients described in the previous section. In their view, the nurse required a three months training period before the scheme could begin. This training included the following components: essential interviewing skills, required knowledge, orientation and assessment.

Essential Interviewing Skills: Particular attention was paid to helping the nurse learn to recognise and clarify the many verbal and non-verbal clues which patients give about their problems.

Required Knowledge: This included up-to-date information about breast cancer, symptoms and signs of recurrence, methods of treatment; physical, social and psychiatric sequelae; different approaches to aftercare; range of breast prostheses; provision of social services and other helping agencies within the community; psychiatric illness, treatment and indication for psychiatric referral.

Orientation: In order to fully understand what patients experienced, the nurse visited the surgical wards, operating theatres, departments of radiotherapy and social work. She had also discussions with ward sisters, clinic staff and social workers.

Assessment: The nurse was instructed in a method of recording systematically how patients were coping, any problems that had developed and what action was taken.
(Maguire et al., 1980a)

All these components of the training programme toward the establishment of the monitoring scheme were important for nurses in order to understand their counselling role.

Maguire and Faulkner (1988) further developed the training in oncology counselling. In 1988 they published an article describing a training programme they developed for people involved in counselling in cancer care. They opened their article by commenting that: "Fortunately, many doctors and nurses who care for cancer patients realise that their difficulties in communicating with patients and their relatives stem from insufficient training and are eager to remedy this" (p. 848).

They described workshops for up to 20 people interested in improving their counselling skills in cancer care. The workshops require three to four days in order to cover the main agenda and permit discussion about how to apply newly acquired skills. The basis for the workshops is that experienced doctors and nurses acknowledge that they find certain counselling situations hard to cope with because they lack the relevant skills.

After an introduction to and beginning of the workshop, participants were asked to identify problems and goals they wanted to deal with in the training course. The authors developed a list from 200 participants which included 10 items of concern:

1) Breaking bad news
2) Patient who has been lied to
3) Basic interviewing assessment
4) Handling difficult questions
5) Dealing with the angry patient
6) Challenging denial
7) Sudden, unexpected death
8) Bereaved relatives
9) Breaking collusion
10) Handling the withdrawn patient

From this list of topics participants wished to deal with, the training programme was established. It included five elements: basic interviewing

and assessment, use of role play, briefing, feedback and problems in counselling.

Basic Interviewing and Assessment: The aspects covered were history of the patient's illness and treatment to date; patient's perceptions, psychological reactions, and view of the future; and the impact of illness and treatment on the patient's daily life, mood, and key relationships. The following techniques were demonstrated: Acknowledging, organising, clarifying, and exploring key verbal and nonverbal cues; how to keep patients to the point and use time optimally while avoiding alienation; encouraging precise accounts so that patients make the effort to remember and describe experiences and feelings fully and accurately; and encouraging the expression of feelings.

Use of Role Play: Role play allowed participants to practice situations they experienced in their work under controlled conditions, and audiotape recording permitted playback and discussion of the role play.

Briefing: The participant playing the patient, relative, or colleague was taken out of the room and was briefed by a tutor who used the participant's real life experience of the problem to develop the brief. The role player then returned to the room to sit down and "get into role" while the tutor briefed the doctor or nurse.

Feedback: The doctor then joined the 'patient' and was asked to begin the role play by asking an open question - for example, what problems have brought you here today? The tutor started the audiotape recording and the role play continued until time out was signalled by the doctor or tutor. Each participant in the role play was asked to comment on how was it going, emphasizing good points first. The group was then requested to highlight what they liked. Only when no more strengths were forthcoming, were constructive criticisms invited by the tutor. The tutor resisted offering solutions to the criticisms unless the group failed to resolve the problem (encouraging the participants to generate their own solutions).

Problem in Counselling: Role play was also used to help participants to learn how to resolve other problems on the main agenda, such as "how to break bad news" and "relate to an angry patient". Explicit briefs were given based on real life situations disclosed by the participants.
(Maguire and Faulkner, 1988).

In this report a description of a training workshop in oncology counselling was offered. However, there was no evaluation as to the efficacy of such training and no description of a feedback concerning the helpfulness of the workshop for the participants.

Roberts and Fallowfield (1990) examined extensively the goals of oncology counselling. They argued that it is necessary to distinguish between: 1) the goals which the counsellor would wish the client to achieve, 2) goals which the client sets for herself, and 3) goals pertaining to the counselling process itself. In this work, through a survey collection of data from 219 oncology counsellors throughout the UK, it was shown that counsellors' goals were related to their place of work (Hospital, community based, or hospice) and to whether or not they have undergone recognised training in counselling or psychotherapy. Surprisingly, less than a fifth of the respondents (17.7%) had had any recognised formal qualification in counselling or psychotherapy. This lack of training together with the finding that only a few respondents belonged to a professional counselling organisation presents a disturbing picture of the degree to which nurses actively involved in providing psychological care are sufficiently skilled to do so.

Fallowfield and Roberts in a later article (1992) further described the same survey results of oncology counsellors in the UK. They commented that their results suggested a consistent picture of counsellors who are often overworked, undertrained, under-resourced and insufficiently supervised. "Their role appears to be better understood by their patients than by their fellow professionals... "(p.114). They concluded that:

> Oncology counsellors fulfill a vital and demanding role which cannot be effectively managed without considerable training, experience and support. Counsellors who are not given the opportunity to obtain supervision or to attend workshops and courses designed to maintain the skills and personal growth

> required are at risk of developing the very problems which they may be attempting to ameliorate in others. (p.116)

These observations are especially alarming in view of findings that establish a significant link between psychiatric morbidity, the inadequacy of information given at the time of surgery, and the lack of emotional support and practical advice from the health care team. Therefore, employing **trained** specialist counsellor nurses to remedy these deficiencies should prevent or reduce these forms of morbidity.

Tait, Brooke, Maguire and Sellwood (1980) stressed that: "The number of specialist nurses continues to increase and yet little systematic evaluation of their work has been carried out, such assessment is essential if we are to identify the effective components of a specialist nurse's role" (p.21).

Some 12 years later, Fallowfield and Roberts (1992) pointed out that:

> Although evidence for the efficacy of counselling is still slender, it seems that consumer demand and the judgement of oncologists that counselling helps will ensure that posts for oncology counsellors will continue to be created. It is important that these often well motivated counsellors are given appropriate training to enable them to offer appropriate help to their patients. Too often, enthusiasm, a sympathetic attitude and experience in working with patients who have cancer are seen as suitable criteria for appointment... We would argue for urgent consideration to be given to improving both the training and the working conditions of cancer counsellors in the United Kingdom and in other countries where oncology counselling is being developed. (p.116)

Wilkinson (1992), based on her research findings discussed earlier on, commented in a similar way that it is important not to use the term communication interchangeably with counselling, which entails good communication skills but also other, specialised skills, and it should not be undertaken without training and supervision. A particular worry, she commented, is that nurses in cancer care are acting as counsellors without receiving appropriate training and supervision.

Research on the Effect of Counselling

The efficacy of a specialised nurse-counselling service in breast cancer care was examined and the results are equivocal (Watson, 1983, 1984). In some studies a reduction in the level of distress in patients who had had specialised counselling was found (Gordon et al., 1980; Linn, Linn and Harris, 1982) but others have either attributed no clear benefits to the counselling treatment (Blake, 1982; Golonka, 1977) or have shown increased anxiety as a result of it (Bloom, Ross and Burnell, 1978; Maguire, Lee, Bevington, Kucheman, Crabtree and Cornell, 1978). It was found by Maguire et al. (1978) that counselling by a specially trained nurse following surgery failed to reduce psychological morbidity and only subsequent intervention by a psychiatrist achieved any reduction in anxiety and depression. These authors suggest that a specially trained nurse would offer more effective support if counselling were commenced as soon as the patient was notified of her diagnosis. This would enable the nurse counsellor to fully discuss the diagnosis and treatment preoperatively with the patient and her family and establish a supportive relationship at an early stage.

In a later study, Maguire, Tait, Brooke, Thomas and Sellwood (1980b) again conducted a controlled trial to determine whether counselling by a specialist nurse prevented the psychiatric morbidity associated with breast cancer and mastectomy. Seventy-five patients were counselled by the specialised nurse and monitored during follow-up sessions, while 77 patients only received the routine care normally given by the surgical unit.

Patients and matched controls were assessed before the surgery, three and 12 to 18 months after operation. This prospective study used self reported data of mood scales examining mainly states of anxiety and depression. The results revealed that counselling failed to prevent psychological morbidity, but that the nurse's regular monitoring of the women's progress led her to recognise 76% of those who needed psychiatric help and refer them to further treatment. Only 15% of the control group whose condition warranted help were recognised and referred to further psychiatric help. Consequently, 12 to 18 months after mastectomy there

was much less psychiatric morbidity in the counselled group (12%) than in the control group (39%). These findings highlighted the high degree of psychiatric morbidity in patients who have undergone mastectomy and indicate the need to identify them at an early stage.

Linn, Linn and Harris (1982) evaluated the effect of counselling on terminally ill cancer patients. Their study assessed the impact of psychosocial counselling on the outcomes of quality of life, functional status, and survival in end-stage cancer patients. Three hypotheses were tested: 1) that counselling would improve the quality of survival, 2) that, if quality of life was enhanced, functional status would be higher, and 3) that if patients felt better about themselves and functioned at a higher level physically, length of survival might also be extended. One-hundred-and-twenty men with end stage cancer were randomly assigned to experimental or control groups; the 62 experimental group patients were seen regularly by a counsellor. Patients were assessed before random assignment and at one, three, six, nine and 12 months on quality of life and function status.

Psychosocial counselling was found to enhance the quality, but not the length, of survival. Thus, the primary hypothesis was proven. Experimental patients had improved quality of life by three months after counselling. Since there was no difference at one month, the authors suggested that it might be concluded that more than one month of counselling is needed to demonstrate change in quality of life. Changes in quality of life, however, were not accompanied by a significant change in physical functioning. It had been hypothesised that if physical functioning were associated with change in quality of life, then perhaps survival itself would be extended. Although quality of life changed, functional status was not influenced, and length of life was essentially the same for the two groups.

Conclusions from the results of this study concerning the effectiveness of specialised oncology counselling are limited. This study involved only end stage male cancer patients. Furthermore, it is not stated in the report whether the counsellor was a trained nurse. Confronting death seemed to be the main issue when counselling these patients, whereas if dealing

with early stage cancer patients, many other issues (such as body image and disability) may be of significant relevance in patient counselling.

In 1988, Watson, Denton, Baum and Greer reported another prospective study examining the efficacy of a specialist nurse counsellor service in breast cancer care. Forty newly diagnosed breast cancer patients, treated by mastectomy, were randomised to receive either routine care or routine care plus counselling by a nurse. Psychological morbidity was assessed at one week, three months and 12 months postoperatively to evaluate the service. Comparisons between the groups indicated that counselled patients were significantly less depressed at three months postoperatively and reported more beliefs in personal control over health. At 12 months postoperatively there were no differences between the groups. Although both groups continued to adjust throughout the year following surgery. This adjustment occurred more rapidly if patients were counselled. Their results, quite different from those of Maguire et al. (1980b), suggested that a nurse counselling service is of value in helping to reduce the amount of distress experienced by the woman as a result of the diagnosis and treatment of breast cancer.

It should be noted though, that this research (Watson et al., 1988) was done a few years after Maguire et al. (1980b) published their initial results on the efficacy of an oncology counselling service, and that by then the real value and effectiveness of nurse counselling and the training in the field had been improved. This might explain the fact that in the later study counselling appeared to be more effective in providing emotional and psychological support to the breast cancer patient.

Measuring the effectiveness of a specialist oncology counselling service, however, is clearly a difficult task. The difficulty is related to the sensitivity of the outcome measure - patient psychosocial well being and satisfaction with the service. All the studies mentioned in this section evaluated counselling by giving patients self reported psychological tests, usually before and a few times after counselling was commenced, thus employing a prospective approach. Such methods may not be sensitive enough to evaluate the desirable outcome measure. None of the studies interviewed patients and/or nurse counsellors in an in-depth manner,

gaining an understanding of their experiences of counselling and their satisfaction with this specific therapeutic relationship.

Conclusion

In order to conclude the review on nurse counselling in breast cancer care, and in order to lead the reader to the following chapter on the phenomenological method of the present study, I refer to an idea described by Burnard (1992). In his article he discussed the problems in understanding other peoples' talk. He examined talk in research (e.g. the phenomenological interview method), in counselling and in psychotherapy. Burnard (1992) argued that what these three have in common is that they are characterised by one or more people trying to make sense of other peoples' utterances. That is where phenomenological analysis of research interviews and psychotherapy meet.

> Both attempt to represent, as clearly as possible, the world of the client or the research respondent. Both try to enter the life-world of the other person in order to understand it. In this respect, both researcher and psychotherapist are similar. Whilst their stated aims may be different, they both have a commitment to honest representation of another person's experience of being in the world. (p.131)

Burnard's conclusion is that we all need to be cautious about what we assume other people to be saying: in research, in counselling and in everyday life. I would further argue that it is not enough to be cautious, but that counselling in breast care requires unique sensitivity and understanding of women - their anxieties, concerns, and role in our changing modern world.

Chapter V:

THE METHOD

Introduction

In this chapter the phenomenological background to the method of the present study is discussed. The theoretical basis for the method is explored and its relevance to the study of the experience of decision-making is elucidated in relation to the treatment of breast cancer. Phenomenology is the study of experience. In a broad sense it is the study of the world as perceived and lived by individuals. A phenomenon can be defined as anything that can be perceived as an occurrence or a fact by the senses. Any experience can therefore be a phenomenon. The phenomenon being studied in this work is the women's experience of choosing a treatment for primary breast cancer and the role of nurse counselling.

The method used in the present work is based on an approach in social research which is aimed at exploring **the quality of experience rather than its quantity**. It is the meaning and content of the phenomenon under study that is of interest to the researcher and not necessarily its frequency or distribution.

The psychology of breast cancer has been widely examined in various studies in a quantitative manner. These studies have explored the many psychological and emotional correlates of breast cancer and nursing implications in a natural scientific and positivistic fashion. For many studies, however, the more recent trend which looks at the quality, meaning and attributes of the examined topic, gaining *Verstehen* - deeper understanding of the object field, has been found to be more appropriate. The qualitative approach used in this study, and the more traditional quantitative method should, therefore, be seen more as complementory rather than exclusive.

The argument in support of the use of a phenomenological method is, still, that only through understanding the **lived through** experience of decision-making of women faced with the diagnosis of breast cancer, can we gain insight into the phenomenon of decision-making in that situation. Furthermore, it is only by gaining insight into this decision-making experience also from the nurses' perspective, that the required

counselling can be explored and the means of adapting it to the needs of the individual can be developed.

The common approach to analysing the decisions taken by breast cancer patients employs statistical procedures. By this method the patients are viewed as a set of observations, their decisions scored in frequency tables, and their expected or modal decisions are defined with the smallest possible statistical error. The advantage of this approach is that the results can be generalised. It enables health care staff to plan the therapeutic strategy most likely to help any one patient. Its drawback, however, lies in its inability to decipher the motives, emotions, fears, disinformation, influence of misinformed, interested or panicking relatives, and the impact of prejudices that lie at the foundation of the **personal** decision and coping mechanisms. Analysis by statistical means describes the "mean" and "deviating" woman rather than **the woman**. The present study, therefore, aims not to provide expected trends, but to learn who the woman is, who is faced with making decisions on the mutilation of her body in the face of cancer and death. The views of nurse counsellors concerning their role in supporting these women are also of major interest.

The sections in the first part of the chapter include a description of the philosophical background that led to the development of phenomenological thinking and a review of the phenomenological method. The specific use of phenomenology in nursing research is explained. Interviewing, as a mean of collecting phenomenological data and entering the **lived world** of breast cancer patients and nurses, is also addressed. Since the present research is based on an investigation by a woman (the researcher) of women (both patients and nurse counsellors), the 'womanistic' aspect and influence of this specific interaction is discussed. Moreover, the specific issue of this study is a disease experienced exclusively by women. In the second part of the chapter the theoretical areas discussed in the first part are integrated to the study on nursing counselling at the point of choosing a treatment for primary breast cancer. The specific procedures of data collection and analysis are presented, and the questions of validity and reliability are discussed. Some limitations of the method are mentioned.

Background to the Method

Phenomenology - The Study of Experience

Many nurses and qualitative researchers in the social sciences have given their own definitions and explanations of phenomenological research. Here are some examples:

> The phenomenologist assumes that there is something in the nature of human, beyond sheer reason or sensory observation, which will produce knowledge... The phenomenological movement is an attempt to understand empirical matters from the perspective of those who are being studied (Davis, 1978, p.186).

> Phenomenological approach focuses on description of experience as it is related to a particular phenomenon (Bates, 1979, p.5).

> In contrast to the empirical models of research, phenomenology seeks to understand the subjective meaning of human experience (Knaack, 1984, p.110).

> Phenomenology, which attempts to study the human experience as it is lived, is not just a research method, but also a philosophy and an approach (Omery, 1983, p.49).

> Hermeneutics and phenomenology are human science approaches which are rooted in philosophy; they are philosophies, reflective disciplines (van Manen, 1990, p.7).

Existential Thought and Phenomenology

The phenomenological approach to life problems in general and to research in particular is rooted in the development of the existential movement in Europe during the 19th Century.

The dictionary of philosophy defines existentialism as:

> A philosophical trend or attitude, as distinct from a particular dogma or system... In the existentialist view the problem of being must take precedence over that of knowledge in philosophical investigations. Being cannot be made a subject of objective inquiry; it is revealed to the individual by reflection on his own unique concrete existence in time and space. (Flew, 1979, p.76).

As a formal philosophical school of thought, existentialism seeks to understand the human condition as it manifests itself in our concrete, lived situations. Its concern in these situations includes not only the physical characteristics (such as the people and places involved), but also the lived through emotions - the attendant moments of joy, absurdity, and indifference - as well as the range of freedom we experience in our responses to these various moments. By contrast, natural scientific methods tend to investigate only the observable, physical aspects of phenomena. Joy, absurdity, indifference, and freedom are a few of the many truly existential phenomena seldom treated by formal science. The most influential proponents of Existentialism in the 19th Century were the philosophers Kierkegaard (who introduced the concept of Existentialism) and Nietzsche, as well as the writer Dostoevsky. In our century the main existentialists are Martin Heidegger, Jean-Paul Sartre and Maurice Merleau-Ponty as philosophers and Albert Camus as a novelist. The French participation in the movement brought greater specificity to the meaning of Existentialism as a philosophy and, with this, greater diversity of thought. The twentieth-Century existentialism has developed into the manner of thinking and seeing now known as Phenomenology (as founded and developed by Edmund Husserl, 1859-1938). According to Husserl (1967), phenomenology is a method which allows us to contact phenomena as we actually live them out and experience them. In his words: "Natural knowledge begins with experience *(Erfahrung)* and remains within experience" (Husserl, 1967, p.51). In Husserl's philosophy, phenomenology sought a solid foundation for knowledge by analysing consciousness and its objects in direct experience. He proposed that all forms of knowledge have their roots in consciousness: consciousness is intentional, that is, it is consciousness of something. He referred to this as 'the world of the natural attitude'.

Phenomenology can be viewed as that philosophical discipline which seeks to understand the events of human existence in a way which is free of certain presuppositions of our cultural heritage, especially philosophical dualism and technologism, as much as this is possible. However, the phenomenologist cannot be placed in one school or category. The major issue that distinguishes existentialists from different schools of thought is that people should not be viewed simply as objects in nature. Rather, the phenomenologist accentuates the total, indissoluble unity and interrelationship between the individual and his world. In the deepest sense, the person is viewed as having no existence apart from the world, and the world as having no existence apart from the person. Each individual and his or her world are said to co-constitute one another. The basic existential unit considered by the existentialist is, therefore, the *lebenswelt,* - the lifeworld that directly and immediately is human experience.

In order to understand a given phenomenon, one attempts to suspend or to put in abeyance one's preconceptions and presuppositions. Husserl (1960) described this process as the base for his phenomenological thinking, by saying: "... I have thereby chosen to begin in absolute poverty, with an absolute lack of knowledge" (Husserl, 1960, p.2). The phenomenologist refers to the process whereby one tries to render these assumptions as bracketing. This is what is also called the *epoche* - a Greek word that means suspension of belief. In order to bracket one's preconceptions and presuppositions, however, one must first make them explicit and then "lay out" these assumptions so that they appear in as clear a form as possible to oneself. The processes of bracketing and explication of assumptions have been found to interact in a dynamic fashion. It seems that as one brackets his preconceptions and presuppositions, more of these assumptions emerge at the level of reflective awareness. The argument continues that the process of bracketing leads at the end to the most basic thing that exists - what he calls the transcendental Ego - the 'I' which is left after a complete *epoche* is achieved.

> The objective world, the world that exists for me, that always has and always will exist for me, the only world that ever can exist for me - this world, with all its objects, I said, derives its whole sense and its existential status, which it has for me, from me myself, from

> me as the transcendental Ego, the Ego who comes to the fore only with transcendental-phenomenological epoche. (Husserl, 1960, p.26)

If there is one word that most aptly characterises phenomenology itself, that word is **thoughtfulness**. In the work of the phenomenologists, thoughtfulness is described as a minding, a heading, a caring attunement - a headful, attentive, wondering about the project of life, of living, of what it means to live a life.

Phenomenology as a Research Method

Traditional scientific research methods have been developed to explain specific phenomena, not the human experience. Many researchers in the social sciences searching for alternative methods, especially in psychology, began to realise the value of phenomenological methods for understanding and explaining the human experience. Phenomenological research is primarily characterised by its beginning in the lifeworld. This is the world of the natural attitude of everyday life which Husserl described as the original, pre-reflective, pre-theoretical attitude.

Phenomenology has been used to examine areas that previously have not been amenable to traditional forms of scientific research, such as personal attitude toward an experience or the meaning that experience has for the individual participant. The question that the phenomenologist aims to answer is: "what is it like to...?" - As opposed to the question, "what is it likely to be?", the interest of the natural scientist.

From a phenomenological point of view, research always entails the subjective experience of the world. Learning the world profoundly implies **being** in the world in a certain way - in the act of researching - questioning - theorising. It is the intentional act of attaching ourselves to the world of becoming more fully part of it, or better, of becoming the world.

> Anything that presents itself to consciousness is potentially of interest to phenomenology, whether the object is real or imagined, empirically measurable or subjectively felt. Consciousness is the only access human beings have to the world, or rather, it is by

virtue of being conscious that we are already related to the world. (van Manen, 1990, p.9)

The basic assumptions of phenomenological research were explained by Knaack (1984) as:

> Fidelity to the phenomena as it is lived. The phenomenological interpretation of living is composed of both experience and behaviour.
>
> Primacy of life-world. Experience within the world as we live it.
>
> Descriptive approach.
>
> Expression of the situation from the viewpoint of the subject.
>
> The lived situation is the basic unit of research.
>
> Biographical emphasis because all human phenomena are temporal, historical and personal.
>
> Presuppositionless description.
>
> A search for meaning. (p. 109)

The primary task of the phenomenologist is to reveal the meaning of an event, that is, to understand the experiences of the participants. Furthermore, Knaack (1984) argued that three general steps are utilized by the phenomenologist to understand human experience from the perspective of the subjects of research:

> **Phenomenological reduction** - setting aside one's preconceptions and presuppositions to more fully understand the meaning of the phenomenon for the individual involved in the experience.
>
> **Imaginative variation** - after one's presuppositions have been consciously set aside, one can begin to imagine the appearance of a phenomenon against the background of various meanings of experience in an attempt to determine what this phenomenon means.
>
> **Interpretation** - the articulation of meanings as they emerge in the phenomenon. The researcher's task, here, is to avoid categorizing a

phenomenon in the context of a known theory, concept, or personal preconceptions. (p. 110)

Quantitative methods also require an independence of the researcher. The data should be studied in such a way that it is not influenced by the researcher. Phenomenological research, on the other hand, recognises, identifies, and incorporates where appropriate the biases of the researcher.

From a pedagogic orientation, van Manen (1990) talked about the idea of explicating assumptions and pre-understandings:

> The problem of phenomenological inquiry is not always that we know too little about the phenomenon we wish to investigate, but that we know too much. Or, more accurately, the problem is that our 'common sense' pre-understandings, our suppositions, assumptions, and the existing bodies of scientific knowledge, predisposes us to interpret the nature of the phenomenon before we have even come to grips with the significance of the phenomenological question... If we simply try to forget or ignore what we already 'know' we may find that the presuppositions persistently creep back into our understandings, beliefs, biases, assumptions, presuppositions, and theories. We try to come to terms with our assumptions, not in order to forget them again, but rather to hold them deliberately at bay and even to turn this knowledge against itself, as it were, thereby exposing its shallow or concealing character. (van Manen, 1990, p.46)

Reinhartz (1983) described phenomenological research as a dynamic process, and concluded that all methods in phenomenology are concerned with the transformation of experience into products which are consensually validated. He suggested that this phenomenological transformation has the following five steps:

> A person's experience is transformed into actions and language that become available to him by virtue of a special interaction he has with other persons. In this case the other is a phenomenological researcher who creates a situation or context in which the person's inchoate lived experience becomes available to him in language. That is the first transformation.

> The researcher transforms what he sees or hears into an understanding of original experience. Because we can never experience another person's experience, we rely on data the subject produces about that experience, and we produce from that our own understanding. That is the second transformation.
>
> The researcher transforms this understanding into clarifying conceptual categories which he or she believes are the essence of the original experience. Without doing that, one is simply recording, and recording is not enough to produce understanding.
>
> The researcher transforms those conceptual categories that exist in his/her mind into a document which captures what he has thought about the experience that the other person has talked about or expressed in some way. That is another transformation. In all these transformations, information can be lost.
>
> The audience of the researcher transforms this written document into an understanding which can function to clarify all the proceeding steps and which can also clarify new experiences that the audience has.
>
> (Adapted from Reinharz, 1983, p.78)

This transformation process was summed up by stating that:

> The way the phenomenon appears is not satisfactory; we must transform it in such a way that it is acceptable to science. This implies a response to the phenomena, otherwise what is there to be transformed? (Giorgi, 1970a, p.83)

It has been suggested that the data analysis process consists of two overlapping phases. In the first phase the researcher must immerse himself in the data and avoid projecting his personal biases onto the material. The second phase requires the researcher to reflect on the data in order to discover themes in the material and to understand and convey, in an organised fashion, the essence of the examined experience.

The data may be presented in a number of ways depending on the researcher's preference. The options include:

An outline of the experience of each individual (as separate case studies).

Development of a fictitious character whose experience represents the average or mean stance.

Presentation of a structural description that outlines the similarities and differences in people's experience.

(Bates, 1979, p.23)

A phenomenological approach enables the researcher to reveal the diverse ways in which individuals understand their own experiences, while retaining the ability to describe common trends and differences in the subjective experience of the examined subjects. This approach allows the reader the opportunity to view many of the original meanings expressed by the participants in a study and interpret the findings in a way that is meaningful for him or her.

Giorgi, one of the advocates of psychology as a human science which takes into consideration man's participation in life events, suggested that phenomenological analysis focused on uncovering the meaning of lived experience through in-depth study of subjects' descriptions. The process according to him includes:

Dwelling on the description.

Returning to the subject for elaboration on ambiguous areas of description.

Identifying natural meaning units.

Identifying themes.

Identifying focal meanings.

Synthesizing of situated structural descriptions.

Synthesizing of a general structural description.

(Adapted from Giorgi, 1985, p.78)

In analysing the data the researcher dwells on each description, identifies questions, and returns to the subject for an elaborated description. The elaborated description is studied through the process of intuiting, analysing, and describing. Each subject's description is examined and natural meaning units, or scenes are identified. The scene, a unit of the description which begins and ends a thought, is examined for emerging themes, which are identified in the words of the subject and are the central elements of the scene. The focal meaning is the crystallisation of the theme, which is written in the language of the researcher and shifts the level of abstraction of the theme. The situated structural description of the subject's description is divided into its focal meanings. This structural description specifies the meaning of the phenomenon from the perspective of each subject. The situated structures for all subjects are synthesised into a general structural description of the phenomenon, which is the meaning of the lived experience of the phenomenon studied from the perspective of the subjects.

It has been further argued that:

> ...the difficulties in trying to avoid the phenomenal layer (even if possible) are more insurmountable than those trying to confront it directly. That is why a real breakthrough in psychology will be achieved when we learn to study the phenomenal domain in its own terms and in a rigourous and specific manner. (Giorgi, 1970b, p.83)

Phenomenology and Nursing Research

Applying philosophical ideas of inquiry to nursing has stimulated some argument. Kikuchi and Simmons (1992) noted that:

> Disillusioned with the positivistic approach to science, many nurse researchers, following the social scientists, have turned to other approaches and, in so doing, have stretched the scope of science as traditionally understood... Science has been expanded to include, among other things, private knowledge, subjective opinion, and description of lived experience, all of which lie beyond objective verifiability. (p.5)

Phenomenology appears to be one of the qualitative research methods most appropriate to nursing research. Other qualitative methods include, for example, grounded theorising (Glaser and Strauss, 1967), ethnomethodology and the pursuit of oral history (as described by Leininger, 1984). Some other qualitative research methods that have been used in nursing studies are symbolic interactionism (Denzin, 1989) and discourse analysis (Potter and Wetherell, 1989). In the present study phenomenological concepts direct the methodological steps of data collection and analysis. A justification for the use of phenomenology in nursing has been put in the following terms:

> Phenomenology represents the effort to describe human experience as it is lived. The nursing profession, emphasizing a reverence for clients' experiences, is concerned with the quality of life and the quality of the nurse-patient relationship. The profession embraces a holistic approach to patient care. Nursing, concerned with lived experience, focuses on interpersonal techniques such as empathy and on concepts of crisis, motivation, stress and perception. In this sense, the philosophy of phenomenology is a promising approach for nurses. (Oiler, 1982, p.178)

The meaning of many concepts in nursing need to be clarified phenomenologically. Dependency, self-care, patient, client autonomy, and health for example, are all concepts that could usefully be clarified with this approach. Munhall and Oiler (1986) pointed out that :

> The phenomenological perspective would lead us to think again about what is real in the experience that just passed. We would hold knowledge in doubt, we would think again and maybe come to a richer understanding about our clients, ourselves, and how to assist. Such understandings are directly related to the development of a body of knowledge and the design of effective nursing care. To contribute to a body of knowledge these understandings must be described. Phenomenological description, therefore, is simply the effective way of insight into human experience. (p.75)

Phenomenology serves as the rationale behind efforts to understand individuals by entering into their field of perception in order to see life as the individuals see it. In order to ascertain the essential structure of a

caring interaction, it would be desirable to learn the client's perception of the caring interaction that takes place between the client and the nurse.

Benner in her work on the concept of care and its relationship to nursing suggested that an examination of the concept of care should not be limited to the use of quantitative methods. She wrote:

> To examine 'care' we cannot rely on purely quantitative experimental measurements based on the natural science model. Nursing is a human science, conducted by self-interpreting subjects (researchers) who are studying self-interpreting subjects (participants) who both may change as a result of an investigation. (Benner, 1984, p.171)

Another writer stated that:

> The nursing profession is proud of its identification as a humanistic discipline. The profession's values and beliefs include a view that the human phenomenon is holistic and meaningful. The phenomenological methods share such values and beliefs. They consider all that is available in the experience under study, both subjective and objective, and strive to understand the total meaning that the experience has had for the participants. (Omery, 1983, p.181)

In this passage Omery did not mention one major aspect of phenomenology, that is the experience of the researcher and the meaning that the study has for him/her, and the participation of the researcher's personality in the study. The researcher's involvement has been described by saying that:

> In fact, the researcher's involvement is exploited in qualitative research. Because the researcher is involved, a range of modes of awareness can be used in data collection. Empathetic and intuitive awareness, for example, are deliberately and purposefully employed. (Oiler, 1982, p.179)

In her book on qualitative research methods in nursing, Leininger commented on the use of phenomenology in nursing research by saying that "Nursing, as a science, has a goal to understand those individuals

being cared for, in order to know how to care for them" (Leininger, 1984, p.63). This is a central motive behind the employment of phenomenological research methods in nursing science. It is only through the true understanding of the client's perceptions and descriptions of experience, that the quality of our nursing intervention and support can be improved.

Omery (1983) summarised her discussion on qualitative research in nursing by stating that: "To be scientific does not mean strict adherence to a specific set of methodologies, rather it is to have boundless curiosity surrounded by discipline" (p.61).

The Phenomenological Interview

In the ideal case, the collection of phenomenological data does not affect the data as they are related. However, the data - human experiences - are collected by verbal intercourse, normally by personal interview, between the subject of interest who has had the experience and the researcher. As a result of this method, the researcher is bound to interact with the examined person and affect his or her choice of related experience and way of talking about it. The researcher may even affect the memory of the experience, and therefore must be very careful in choosing the way of approaching the subject of interest. Beginning with the invitation to participate in the study and through the interaction with the interviewee, the researcher has to show genuine honesty and true interest. He or she must convey uncritical acceptance of the subject and his or her narrative and a full commitment to serious and impartial treatment of the personal story that has been allowed access to.

Through dialogue, the interview becomes a joint reflection on a phenomenon, a deepening of experience for both interviewer and participant. It becomes a conversational relationship between two people. One in which they come to learn as much about each other as they learn about whatever is the topic of conversation. The sensitivity of this relationship was described in the following terms:

> The interview experience holds a potential for the development of trust and commitment, and for the growth of a new human relationship, and new or deepened understanding. But that which makes these things possible, also holds the potential for abuse or betrayal... As do all human encounters, the interview involves risk for both parties. The risk of exposure and the call to commit one's oral discourse in an exceptional way is often one-sided in the interview situation, both the researcher and the participant knowing full well that the focus of analysis will be on what the participant says, not on the fumbling words of the interviewer. (Weber, 1986, p.70)

The potential for abuse and betrayal in the interview experience is, however, accompanied by the potential for developing trust and shared understanding. How that potential is fulfilled might depend on the nature of the particular interview experience itself, on the nature of the relationship between interviewer and participant and on the preconceptions and power relations they bring to the interview. Additionally, the development of trust or abuse may also depend on what happens after the interview is over, when the researcher decides how to deal with the experience, or indeed the interviewee.

An interview can never be simply a conversation by virtue of the fact that it is usually recorded and transcribed, and invariably written down. An interview becomes the spoken word captured with the permanence of a written document.

The mode of understanding in the qualitative research interview was outlined by Kvale (1983) in the following 12 aspects:

1) centred on the interviewee's life-world
2) seeks to understand the meaning of phenomena in his/her life-world
3) qualitative
4) descriptive
5) specific
6) presuppositionless
7) focuses on certain themes
8) open for ambiguities
9) changes
10) depends upon the sensitivity of the interviewer

11) takes place in an interpersonal interaction
12) may be a positive experience.

(Kvale, 1983, p.174)

The interviewing process is composed of six possible phases which do not necessarily presuppose each other logically or follow chronologically:

1) The interviewee describes his life-world.

2) The interviewee discovers new relations, sees new meanings in what he experiences and does.

3) The interviewer during the interview condenses and interprets the meaning of what the interviewee describes, and may 'send' the interpreted meaning back. The interviewee then has the possibility of replying "I did not mean that" or "that is precisely what I was trying to say" or "no, that was not quite what I felt".

4) The completed and transcribed interview is interpreted by the interviewer alone.

a) The interviewer attempts to condense and formulate what the interviewee himself understands as the meaning of what he describes.
b) Going beyond what the interviewee himself experiences and means about a theme, while remaining on a broad common level of understanding.
c) Interviewer may draw on more theoretical interpretations, as e.g. psychoanalytical theory of the individual.

5) A re-interview. When the interviewer has analysed and interpreted the completed interviews, he may give the interpretations back to the interviewee. In the re-interview the interviewee may comment upon the interviewer's interpretation of his statements, and the themes touched upon in the first interview may be deepened in the re-interview.

(Weber, 1986, p.66)

Since the phenomenological observation of experiences is based on personal interaction, it might be viewed as a source of error when different interviewers using the same interview guide vary in their sensitivity to the themes investigated, and obtain different aspects and

levels of the interviewee's relation to these themes. Within a phenomenological understanding, however, the fact that interviewers vary in sensitivity is rather an advantage. They may collectively be able to obtain a broader picture which is richer in its nuances of the themes in question. While varying sensitivity among interviewers may reduce the reproducible information, which provides reliability in the traditional sense, it will yield a wider picture of the themes in research. In a focused phenomenological interview, the major objective is to learn about certain themes in the life-world of the interviewee, avoiding the specific interpretations of these themes.

A method of research may be considered valid when the resulting observations pertain to the object of research. One measure of validity is content validity. It indicates the extent to which a method investigates the content it is intended to investigate. In the qualitative research interview, this requirement involves the extent to which the interviews investigate the meaning of the lifeworld themes that are relevant to the interviewed person.

Interviewing Women

Oakley (1981) identified two separate types of interviews that are mentioned in methodological textbooks. In the first, the interviewer is compared to a combined phonograph and recording system. Her job is fundamentally that of a reporter. The second type is therapeutic. The relationship between the interviewer and interviewee is in both cases hierarchical and it is the expertise of the interviewer that determines the success of the interview. She suggested, therefore, that the entire paradigmatic representation of 'proper' interviews in the methodological textbooks can primarily be traced back to a masculine social and sociological vantage point of view that is associated with such values as subjectivity, detachment, hierarchy, and 'science' that take priority over people's more individualised concerns.

In a study of women's attitudes toward contraception-free love-making, Hollway (1989) discussed the significance of subjectivity in social and

psychological qualitative research from a feminist point of view. She argued that the personal interview is the most appropriate method of data collection in female social psychology; in view of the hypothesis that women's experience can provide a direct route to women's consciousness or identity. It is assumed that women especially attach existential meaning to personal experience, so that asking women directly for an account will lead them to expose their inner existential frustrations of their experience (Hollway, 1989).

Baker (1990) expressed the opinion that research of women gives them the opportunity of talking about their life as they experience it; about their values, hopes, and the adjustments and compromises they choose to make in order to maintain family harmony. In the analysis, the female researcher can recognise the negotiations and ambivalence about which women speak better, and has more personal insight into the meaning of what women express than the male researcher.

When a woman interviews women, it appears that the goal of the interview is best achieved when the relationship of interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship.

> It requires that the mythology of 'hygienic' research with its accompanying mystification of the researcher and the researched as objective instruments of data production be replaced by the recognition that personal involvement is more than dangerous bias - it is the condition under which people come to know each other and to admit others in their lives. (Oakley, 1981, p.53)

The present study on breast cancer has a feminist orientation. It is the account by women of an experience which is unique to women - the confrontation with the diagnosis of breast cancer and the decision-making regarding their treatment. The primary issue is the breast, a symbol of femininity and sexuality. The accompanying themes are also feminine in nature, as for example, the role of these women as women, their sexual concerns in a male dominated society, and their need to face a male doctor. The researcher is a nurse and a woman herself, and the range of her experiences is by nature related to these facts. All these issues stress the

need for a deep consideration of the "womanistic" aspect of the study with respect to the phenomenological methodology. The primary concern of this work is the understanding of women at the level of their subjective/personal existential frustrations and gaining a phenomenological insight into their world as women faced with a diagnosis of breast cancer and with the decisions to be made regarding their treatment.

Phenomenology and the Present Study

In this part of the chapter the actual steps of data collection, and the consequent process of analysis that were carried out in the study, are described.

The Pitot Study

The main study was preceded by a small pilot study with several objectives in mind:

1) To test the method of approaching the women for interviews and compose the letter of invitation to participate in the study.
2) To develop interviewing techniques and skills.
3) To get feed-back from the respondents about my interviewing capability.
4) To test the validity of the method, that is, the ability to collect the data necessary for answering the specific questions using the planned procedure. The strategy chosen was that of an open interview followed by a list of specific topics for discussion.
5) To practise transcription methods.
6) To try and achieve a first level of analysis of the data.

Contact with the specialised breast unit was established through the breast care nurse counsellor. My letter inviting women to take part in the study was given to women visiting the breast clinic (see Appendix 1). Ten letters were distributed and six women contacted me to schedule an interview. This response seemed sufficient and fitted my expectations and indicated that the letter was the right method for approaching the women. Since the topics to be discussed were very personal, sensitive and possibly threatening, it was expected that not all the women receiving a letter

would be willing to talk about such issues with a 'stranger'. Furthermore, this study was not performed in direct association with psychiatric staff who could help women overcome the psychological stress that might result from an interview they were not capable of dealing with. Therefore, it was thought that the best way of approaching these women was by the least threatening manner, by delivering them a letter through the ward staff and leaving them the decision whether to contact me or not, with no further influence on my behalf. For these reasons, despite the risk that because of laziness or that it meant a special effort fewer women might respond, this method of approaching the women was accepted.

The six women were interviewed. Each interview lasted between 75 and 90 minutes. The list of topics developed to guide the interviews is given in Appendix 2. This list was developed from the main questions that the study aimed to answer, and from earlier informal conversations with breast cancer patients. All the interviews followed the same sequence of topics and had a similar overall structure. They were later transcribed, analysed and formed the basis of the main study. Each transcription was sent to the respective interviewee for comments and validation. All six women responded in a positive manner to the transcripts and the experience of the interview. They confirmed that the transcripts were a faithful record of the interview. They also ascertained that the level of distress involved at the time of interview was acceptable, or that they were not badly affected by the experience.

The first level of analysis of these interviews served to develop and adapt the method to meet the requirements of the present work. For this purpose, the content of the interviews was divided into their component themes which were then classified under the following main categories:

1) Reaction to first being informed of cancer: 'not taking it in'.
2) Participation in the choice of treatment.
3) 'Just want it away'.
4) Nursing counselling - ideas and definitions as seen by the women.
5) Patient to patient support.

An elaboration on the theme, 'Just want it away' was then carried out. The women's views regarding this concept were examined in particular detail. A report of the pilot study was written and was presented to the research support group for discussion. This group included the two academic supervisors, the specialist breast care nurse counsellor and the senior consultant of the breast unit. The main conclusions of that meeting were firstly, that in the main study the letter inviting the women to participate in the study would be given personally to the women by the nurse counsellor since she had the most contact with these women. Secondly, that it would be given only to women who were known to have been actively involved in a decision-making experience about the treatment for their primary breast cancer. Thirdly, it was decided that in the interviews there should be more concentration on themes relating to the choice of treatment and the nursing counselling involvement. Finally, it was felt that the list of topics guiding the interviews was appropriate and therefore would be used in the main study.

The Main Study

In the main study, both women with breast cancer and nurses involved in a specialist breast cancer counselling service were interviewed.

Recruitment of Respondents

The Women -

Seventeen invitation letters were delivered to women through the nurse counsellor of the specialised breast care unit. Ten women responded and were interviewed. These women had primary breast cancer and underwent a decision-making experience concerning the treatment for their cancer. A detailed description of each individual woman is given in Chapter Six. The women contacted me spontaneously in response to my letter of invitation (the same letter as used in the pilot study, see Appendix 1). I deliberately avoided approaching the women myself so as not to influence their free choice of whether to contact me or not. I wanted to talk only to women who were actively prepared to talk to me. I believed it to be an important element when trying to enter such a sensitive topic.

For the ten women who contacted me, an interview was scheduled at a time and place most comfortable for them.

The Nurse Counsellors -

Through a list of the Breast Care Nursing Network in Scotland, seven nurses working as specialists in breast cancer counselling were identified. One was the counsellor at the local unit from where the women in this study were recruited. The other six worked in various parts of Scotland. A letter was sent to all these nurses inviting them to take part in the study (see Appendix 2 for the letter of invitation to nurse counsellors). All the nurses responded positively to the letter of invitation and a time for an interview was scheduled.

Data Collection

Interviews with the Women -

From the ten interviews with the women, four took place at the home of the interviewee, and six in my office at the university. The interviews lasted between 75 minutes and two hours. As in the pilot study, a list of topics guided the interviews and gave them a rather similar uniformed structure (See Appendix 3 for topics for interviews with women). These interviews were tape recorded and later transcribed. Two examples of transcripts of interviews with women can be found in Appendix 4.

At the beginning of the interview I introduced myself, and the project that I was engaged in. I thanked the woman for coming (or for having me in her home, when the interview took place there) and for her willingness to take part in the study. At that point I left time for questions before we proceeded with the actual interview. In many cases, the woman wanted to know more about my background and the study. After answering these questions, I asked permision to switch on the tape recorder. None of the women refused to have the interview tape recorded. The first question that I asked was open, and gave the woman the possibility of starting to talk about her experiences in relation to her breast cancer. I asked the woman to tell me about the course of events and happenings that led to the diagnosis of her breast cancer. This question was thought to be non-intimidating, leaving the woman with the possibility of either sharing

with me personal and emotional experiences, or just being factual and telling me the diagnosis and treatment in an objective, more distant manner. It turned out that most of the women straight away started discussing their feelings and were extremely open in their talk. The experience of interviewing from my point of view is more fully discussed in Chapter Nine. As mentioned before, the interviews were somewhat guided by a list of topics for discussion, but were generally very open thus enabling the woman free expression.

An interview of such a type is a special sort of interaction. It is a situation where two people who are basically strangers meet and very quickly communicate on a personal level. A relationship of trust needs to be established and confidentiality must be ensured. It was for this reason that at the end of each interview I asked the woman how she felt about the interview and the experience of having talked about such personal matters. All the women said they were only too happy to help and take part in such a research, and all of them but one expressed the feeling that they found it helpful and rewarding to discuss their experiences relating to the illness. Only one woman (who will later be referred to as Sandra) mentioned the fact that she found it difficult to talk about her breast cancer and that it was particularly hard for her to find the right words to express her feelings. However, she also said that it was in many respects worth while and was happy to be of any further help.

A further source of data for the main study was a collective discussion held with 12 women who attended a meeting of the 'Reach for Recovery' group. This group belongs to a local self-help initiative of women who have undergone treatment for breast cancer. The participants meet for a social gathering to discuss and share various issues and problems related to their experiences associated with their disease. The group initiative provides a strong form of support for many of these women. Volunteers from the group also visit breast cancer patients in the hospital and discuss with them practical as well as emotional matters. I joined one of these meetings with the aim of directing a discussion on the main issues of my study, namely, patients' participation in the choice of treatment and the nursing counselling offered. The aim of this group discussion was to obtain a collective view of these women, in contrast to the individual

interviews. The interaction between the women was of special interest. Each woman was actively involved and the discussion was stimulating and interesting. They had a lot to say and views to share about the topic. The discussion lasted just over two hours and was also tape recorded and later transcribed. A full transcription of the 'Reach for Recovery' group meeting is given in Appendix 5.

Interviews with Nurse Counsellors-

The interviews with the nurse counsellors were a relatively straight forward process. In six out of the seven interviews the meeting took place at the work place of the nurse. One interview happened in my office in the university, since the nurse thought it more comfortable to have it there and that there we would have a better opportunity for a quiet and relaxing environment. Like the interviews with the women, these interviews were of a rather unstructured nature and followed only a general list of topics for discussion (See Appendix 6 for the list of topics for discussion with nurse counsellors). All the nurses were pleased to talk about such issues related to their work and it seemed that for some of them it provided a unique opportunity to share their experiences and thoughts. This was so especially for the ones who were more isolated in their everyday work. The interviews lasted for about one and a half hours. In most cases, however, I spent a few hours with the nurse - having an informal talk over a cup of coffee. At the beginning of the interview I asked permission from the nurse to tape record our conversation. None of them objected to the interview being tape recorded. These interviews, therefore, were also tape recorded and later transcribed. In Appendix 7 two examples of interview transcripts with the nurse counsellors are given.

In these interviews, as well, I tried to start by asking a general, non-intimidating question. I asked the nurses to describe the medical practice of breast cancer which takes place in their setting. This was found to be an appropriate question to start the interviews with. It usually led the nurses to further talk about their more personal and individual experiences and thoughts.

A most interesting part of the interviews was to learn about the different practices in the various settings. Although the nurses often held similar

job titles, the actual work they were involved in was of a rather different nature. The different attitude to their work and their different understanding of their role was also of major interest. This will be further elaborated in the following chapter (Chapter Six) where a general description of the nurse counsellors and their work will be given.

Data Validation

The transcripts of the individual interviews with the women were sent to them for validation, correction and comments. The accompanying letter sent with the interview transcript is given in Appendix 8. Each woman sent the transcript with her comments back. They validated the transcript and their comments were generally positive. Some women added new ideas and elaborated on specific themes. Their comments on the experience of the interview and the accuracy of the transcript appear in Appendix 9. In the case of the 'Reach for Recovery' meeting, the transcript was sent for validation to the head of the group who had been present at the meeting.

The interviews with the nurse counsellors were not sent back to the interviewees for validation. This was for two main reasons. The first was that the interviews represented a sharing of knowledge between two professionals, and as such were of a very different nature to the interviews with the women. The second reason was that these interviews were transcribed professionally by a local English native speaker and therefore it was thought that there was no need to validate their accuracy. This is in contrast to the interviews with the women which were transcribed by myself. Since English is not my first language, in the case of the interviews with the women I felt the need to gain validation and comments to the transcripts.

Interpretive Analysis and Themes Emergence

The transcripts of the ten individual interviews with the women, the 'Reach for Recovery' group discussion, and the seven interviews with the nurse counsellors were subsequently subjected to an initial analysis of topics and themes. All the transcripts were formatted on half the width of

the paper, leaving wide right-hand-side margins for comments and notes. Furthermore, lines were numbered so that when isolating sentences or parts of the transcript, reference to them was possible.

At the first stage of the process of analysis, each interview was read a few times in order to get familiar with the text and provide a possibility to 'dwell in the data'. The tape was also listened to again at that point. In the case of the interviews with the women, the analysis then proceeded by writing a paper (referred to as 'story') about each of the individual interviews. In this paper what was discussed and told by the woman was described in my own words, giving my interpretation of the content of the interview. This enabled a certain distancing from the text and an 'objective' account of the facts mentioned in the interviews. The 'stories' varied in length but were on average about ten pages long. In the case of the interviews with the nurse counsellors, a short paper was written about each nurse and her work in breast cancer care.

In the second phase of the analysis process, I returned to the original interview transcripts. Coding for specific themes and concepts was then established. This coding served to examine all the interviews in a horizontal cross-sectional comparative manner in order to detect common themes and concepts.

As an example I refer to one theme defined as 'being alone and feeling lonely'. When reading the texts of the interviews, it was noted that most of the women mentioned the loneliness associated with the decision-making experience. In every interview, therefore, the words lonely, alone and loneliness were searched. The context of the paragraph where it was mentioned was then coded and categorised. After this was done for each interview, the codes were examined throughout the interviews. At this stage the theme 'being alone and feeling lonely' was defined and discussed. A short paper on each theme was written. The same was done for all the other themes that had been identified while examining the narratives of the interviews. Twelve themes have emerged in relation to the experience of decision-making and six themes emerged in regard to the role of nurse counselling. See Appendix 10 for a list of these themes. In

chapters seven and eight these themes will be fully discussed and reference will be made to relevant literature.

Validation of the Analysis

The next stage was to jointly meet the ten women as a group and discuss with them the first interpretation of the narrative they provided. This meeting allowed me to discuss the specific themes that had emerged from the initial analysis of the individual interviews. The discussion served as a check of the analysis of these interviews.

It was decided to meet the women together at that stage and not separately for two main reasons. Firstly, this form of meeting was hoped to be less intimidating and threatening. It was thought that some of the women might have pushed the experience of breast cancer to the 'back of their minds' and so another individual interview would perhaps be inappropriate. At the group meeting no personal matters needed to be discussed. The second reason for a group meeting was to receive validation of the first level of analysis by the women collectivly. This was thought to be important and would deepen the interpretation and understanding of the interviews to a different level of abstraction.

About six months after the individual interviews were done, a letter was sent to the ten women inviting them to the group meeting (see Appendix 11 for a letter of invitation to the group meeting). Seven women responded positively and agreed to come to the meeting, two wrote that they were unable to attend because of practical reasons, and one woman wrote that she would not be able to come without specifying the reason. The meeting took place in my office at the university. The experience of that meeting was of great value to the study and seemed extremely rewarding for the women as well as for myself. The atmosphere at the meeting was positive and pleasant and there was lively interaction amongst the women. The themes that were produced during the process of analysis were discussed one by one and the women's comments were extensive and interesting. In general, they validated my understanding of the interviews. This meeting was also tape recorded and major parts of it transcribed. The tape of this meeting was particularly difficult to transcribe

because of the simultaneous lively interaction between the women. Extracts form the transcription of the group meeting with the women who were individually interviewed appear in Appendix 12.

Limitations of the Method

The main limitations of the method used were connected to the means of data collection, the phenomenological interview. The aim of the study was to enter the **lived world** of the women and gain an insight into their experience of breast cancer. Furthermore, the role of nurse counselling was examined from both the women and the nurse's point of views. The interview method, which was perceived as the best method to adopt in order to establish such an understanding, was not, however, free of limitations.

The major limitation concerned the issue that as researchers we must assume that the respondent has been telling us the truth regarding the experience under investigation. The respondents' accounts may not necessarily, however, represent all their **real lived world**.

> The informant's statement represents merely the perception of the informant, filtered and modified by his cognitive and emotional reaction and reported through his personal verbal usage... and we are getting it only as he is willing to pass it to us in this particular situation. (Dean and Whyte, 1969, p.105)

Dean and Whyte (1969) continued their explanation by noting that there are factors which the researcher can expect to influence the informant's reporting of a situation during an interview. These are typified as:

1. Are there any ulterior motives which the informant has that might modify his reporting of the situation?

2. Are there any bars to spontaneity which might inhibit free expression by the informant?

3. Does the informant have desires to please the interviewer so that opinions will be well thought of?

4. Are there any idiosyncratic factors that may cause the informant to express only one facet of his reaction to the subject?

(Adapted from p.107)

Each researcher engaged in using such a method should address these questions, while recognising the limitations which they may pose for the analysis and understanding of the data gathered.

In the present study, the women and the nurses interviewed shared some of their most intimate experiences. The prerequisite of their ability to express what they believed to be their true feelings and thoughts was assumed. The women's and nurses' words were accepted as representing the reality of their lived world. As a researcher, I took into account the questions raised by Dean and Whyte (1969) and, therefore, made every effort to diminish the limitations as far as possible and ultimately regarded the data as being reliable and valuable.

Summary

The present work examines the decision-making process of breast cancer patients in order to formulate the objectives and methods for breast cancer-oriented nursing counselling. It is a phenomenological study based on interview analysis. Rooted in modern existential philosophy, phenomenology aims to describe and understand experience - the world as it is lived. This study, therefore, is concerned with people, their experiences and their reactions to life events as they perceive them. Rather than being able to achieve objective generalisation by quantitative methods, the phenomenological methodology aims to comprehend people's subjective experiences in particular situations. It is believed that only through understanding the every day experiences of people, can a true insight into their **lived world** be reached. This is especially important for counselling patients who have to meet existential decisions in an extremely stressful situation.

Access to the **lived world** of women with breast cancer was gained by verbal interaction in the form of personal interviews and group discussions. Access to the perceptions and views of the nurse counsellors was also gained by individual interviews. The separate accounts were thematically analysed and compared on the basis of the specific themes. Requirements for the work were: the free choice of the respondents to participate in the study, undertaking the interviews where the woman and the nurse felt comfortable to talk, employing good interviewing techniques, and validation of the transcripts by the interviewees, when needed.

Chapter VI:

THE SETTING AND THE PARTICIPANTS

Introduction

In the first part of this chapter, the setting of the local specialised breast cancer unit, from where the women were recruited, is described. The practice employed in the unit, regarding the involvment of the women in the decision-making regarding their treatment, is especially referred to. The 'breast cancer stories' of the women who participated in the main study are then given individually.

In the second part of the chapter, seven nurse counsellors working in breast cancer care in various parts of Scotland are introduced. The nurse counsellors are not described individually, but rather as a group. The reason for that is, because of the small number of nurses employed as counsellors in breast care in Scotland, an individual description of the nurse and her work may identify her to the reader. The account is therefore of a general nature.

The Setting of the Study of the Women

The women were all treated at a specialised breast cancer unit. This unit is the main local place where women are diagnosed and treated for breast cancer. It is also considered to be one of the major centres in Scotland for breast cancer research. Women from all over Scotland come to be seen by the specialists and consultants working at, or in collaboration with, the unit (two surgeons, one pathologist, one oncologist and one radiologist). It is, however, a small unit which has only nineteen beds for hospitalised patients. It was recorded that during 1992 about 4500 women were referred to the unit, and 410 women were newly diagnosed as having breast cancer. On average, five to six breast operations are done during week days, adding up to almost one thousand operations annually.

In general, the philosophy of the unit is to make the experience of breast cancer as untraumatic as possible for the individual woman. For this reason, a homely atmosphere is created where women are hospitalised together in one place and are treated and referred to as individuals, and not as patients. Soon after the operation, the women are encouraged to

dress up in their own clothes in order to make them feel 'as normal' as possible. Support is available from many sources: the nursing staff, other women hospitalised together, self help group volunteers and the nurse counsellor. Still, every woman has her own means by which to find support. The staff encourages the partners, family and friends to be involved and support the woman throughout the hospitalisation period, and the 'breast cancer experience' as a whole. A psychiatrist is also attached to the unit, to help women who experience severe emotional and psychological problems.

Beyond the ethos and the positive atmosphere at the unit, the place is one of the leading hospitals in the UK in terms of the medical treatment it provides for women with breast cancer. The unit is connected to a teaching hospital and as such is involved in advanced medical research. Furthermore, breast reconstruction (immediate or delayed) is offered to every woman when possible, and the fitting of a prosthesis is also done by a professional, when needed.

Concerning decision-making, it is the philosophy and practice to involve the woman as much as possible in the choice regarding her treatment. However, medical recommendations when they exist, are presented to the woman in a clear and direct manner. From a medical perspective, there are usually three main areas where the woman may be actively invited to make decisions regarding her treatment:
1) the type of surgery,
2) taking part in a medical trial, usually evaluating adjuvant therapy, and,
3) method of reconstruction - the type and timing of the procedure.

Choice of Surgical Procedure

In the case of early stage disease, which is localised and is not centred around the nipple, the woman may be asked whether she would prefer to preserve her breast and have radiotherapy, or whether she would choose a mastectomy, usually with no additional therapy. The options are given to the woman with some relevant information on each of the treatments. It is well explained to the woman that the options are presented before her because in her case there is no indication that one treatment is medically

preferable to the other. The woman is then always given the possibility to ask the consultant any questions and to go and further discuss her choice of treatment with the nurse counsellor. The counsellor, often encourages the woman to talk to other women who had either types of operations.

Participation in Medical Trials

At the time when the main study was carried out, a large medical trial examining the treatment for primary breast cancer was conducted in all Scottish University Medical Centres treating breast cancer. The trial evaluated additional (adjuvant) treatment in the case of breast conservation, for early stage disease. Women were invited to take part in the project and consequently be randomly allocated to have chemotherapy, radiotherapy or hormonal therapy. However, there was no pressure being placed on the woman to decide to join the trial. An information sheet describing the trial was given to all women fitting the criteria of the trial (see appendix 12 for the information sheet on trial). Other medical trials were also in progress and were described to the women. The women always had the opportunity to discuss the trials with the nurse counsellor. The counsellor reassured them that if they decided not to participate in the trial, it would not affect in any way their future treatment, and that it was a complete free choice of theirs.

Choice of Reconstruction

If a mastectomy is performed, the woman is usually given the choice of reconstruction. Two issues are considered and discussed with the woman: the timing of the reconstruction - i.e. whether the reconstruction will be done at the initial mastectomy operation, or later as a separate surgical procedure, and the type of reconstruction. The two main types of breast reconstruction are the tissue expander and the flap. The tissue expander is a method by which a silicon implant is placed in the chest wall and fluid is injected in to it, usually at weekly intervals until the desirable size of breast is achieved. This may involve a few months of weekly visits to the hospital. The flap is a method by which muscles and tissue are dragged from the back in order to reconstruct the breast. This is a one stage procedure that does not involve further treatment and can be done at the

initial mastectomy operation. After the surgery, however, rehabilitation may involve up to two weeks of hospitalisation.

At the breast care unit where the study was conducted, these are the main areas where women may be invited to make decisions regarding their treatment. Still, each of the women in this study participated in a different decision-making concerning her treatment, and was given different options from which to elect her therapy.

The Women and their Stories of Breast Cancer

Ten women with primary breast cancer were interviewed. All the women were Scottish and most of them lived in the Edinburgh area. They had all been diagnosed as having early stage breast cancer and were treated at a local specialised breast care unit. The common experience these women shared was having gone through a decision-making process regarding their treatment. Each of the women had a somewhat different treatment and participated in different decisions relating to her treatment. For example, one woman had to make a decision about whether to join a medical trial or not for her adjuvant treatment; whereas, another woman was involved in the choice of the method for reconstructing her breast. This latter woman could choose between the insertion of a tissue expander and a flap construction. I would argue that the fact that the decisions varied from woman to woman, gave greater understanding of the phenomenon of decision-making in breast cancer care. The twelve women who took part in the discussion group at the 'Reach for Recovery' meeting are not described individually, since it was their group identity which was of greater importance for the purposes of the particular stage of analysis.

The stories of the women described in this chapter draw upon my understanding of what was said in the interviews, that is their phenomenal world concerning the actual course of events leading to the decisions regarding treatment. The stories will be narrated in past tense, though this does not imply that any of the women has died. Indeed, all of them were generally doing well. The names are all fictitious.

JILL

Jill was 41 years old. She was married and had one son aged sixteen. Her mother in law lived with the family. Two members of the family experienced major illness before Jill was confronted with the diagnosis of breast cancer. Her mother in law, to whom Jill felt very close, had had cervical cancer a few years earlier. In addition, Jill's husband was still recovering from a heart attack suffered some months before her discovery of the lump. Jill worked part time as an auxiliary nurse at a local hospital.
The lump was found by Jill herself, and she approached her G.P. immediately. He sent her to the specialised breast cancer unit. The tests carried out there confirmed a malignant tumour. Jill was then faced with two options of treatment. At first Jill was told that she could have a lumpectomy done followed by six weeks of radiotherapy. Then, the doctors changed their minds and suggested that a mastectomy would be preferable. It was left up to Jill to decide. In effect this was not a real case of choice, she just had to give her consent to the operation that meant a removal of the breast. Jill gave her consent to the mastectomy. The operation was done and she recovered with no complications. At one of the regular check-ups after the operation the doctor told Jill that further treatment was needed because some of the lymph nodes that had been removed at the operation were positive. The treatment had therefore to be a systemic one. Since the tumour was found to be estrogen related, another operation to remove the ovaries would be appropriate. The second possibility was a course of chemotherapy. The decision was again given to Jill, to choose which treatment she would prefer. There was no doubt in Jill's mind that she would have the ovarectomy. The chemotherapy treatment frightened her too much. However, she was clear that if she had no option, then she would have accepted chemotherapy: "One should fight the cancer and try everything possible to kill it", she said. Jill, therefore, had to make decisions about her treatment twice. The second operation was done and her recovery this time was difficult and painful. In her words: "The experience of the two operations could not be compared". At the time we met Jill was recovering from the ovarectomy. Injections of fluid have been started into the tissue expander, which was put in at the initial mastectomy operation. These injections are usually

started immediately after the insertion of the expander, but were postponed in this case because of the second operation.

MANDY

Mandy was a 60 year old woman who was married with three sons. Her job as a shop assistant in a bakery was one which she enjoyed. Mandy and her husband shared a hobby playing Bridge. They were both active members of a Bridge club which provided their main circle of friends.

One day Mandy felt shooting sort of pains around the nipple. She examined herself and felt a small lump. Her G.P. confirmed the presence of a lump and sent her to be examined at the specialised unit.

At the hospital, a cancerous tumour was diagnosed. To begin with, Mandy was given the possibility of choosing the treatment - a mastectomy or a lumpectomy plus radiotherapy. But, when Mandy saw the radiologist a new perspective was put on this choice. Mandy had had a heart attack when she was thirty five, and it had left her with angina pectoris. The radiologist said that there was a slight chance that the radiotherapy would affect her heart. This added an important factor to be weighed when making her decision.

Mandy could therefore decide without much hesitation to have the mastectomy, the threat of the risk to the heart was too big. She decided instantly that she would have her breast removed. It was really the doctor's recommendation that influenced Mandy and as she said in the interview: "If you have faith in your surgeon, you have to do what he tells you. The doctor is the one with the expertise". Even though the doctors apparently didn't tell Mandy what she should decide - their recommendation was very strong: 'Don't take the risk of the radiotherapy'. All the doctors thought that she would be better advised to have a mastectomy done. Deciding not to have the mastectomy and taking the risk of the radiotherapy would have meant going against professional advice.

There seemed to have been a great deal of support for Mandy from her family and friends. Apart from one sudden breakdown she had, when she felt very depressed, she coped emotionally well, describing it as 'non-traumatic'. She accepted the operation and was determined to go on with her life. Despite this, however, she was not willing to have another reconstruction operation. When we met, about six weeks after her mastectomy operation, Mandy was looking extremely well and was talking about going back to work shortly.

SUSAN

Susan was 42 years old and lived with her boy-friend. She was a beauty therapist and had her studio in her home. Outward appearance was very important for Susan. This was obvious from her appearance as well as her home, which was a beautiful place. One day Susan discovered a breast lump, she rushed to her G.P. who sent her for screening. The mammography result at first seemed clear, but later on she was told that as there was some dubiety, it would be advisable to have a biopsy. The biopsy result confirmed that Susan had a malignant tumour.

At that stage it was decided by the doctors that Susan should have a mastectomy. The tumour was over four centimetres in size, which is an accepted medical indication for mastectomy. Susan gave her consent for the operation. The choice that was given to Susan was whether or not to participate in a medical trial dealing with chemotherapy. The trial aimed to ascertain whether chemotherapy given before or after the operation had the better effect. Susan wanted to be helpful and joined in the trial where patients were allocated on a random basis. By this means it was decided that she would have all the chemotherapy sessions after the operation. After the results of the tissue and the lymph nodes examinations were known, it confirmed that she was actually not in the need of chemotherapy.

Breast reconstruction was offered to Susan. She was young and enjoyed life so the doctors assumed that she should have an immediate reconstruction, and they didn't really give her a choice regarding that. The choice that was offered to Susan was what sort of reconstruction would

she have. She could have a tissue expander or a flap done. The tissue expander is a method by which a silicon prosthesis is put in at the initial operation and fluid is later injected to it until a proper size of the breast is achieved, a method that might take a few weeks. The flap involves dragging muscles and tissue from the back, which means that the breast is immediately reconstructed, and is a big operation that entails at least ten days of hospitalisation. However, the options were taken away from Susan since the doctors said that the tumour was lying high up in the breast and it would be much easier therefore to have the flap done. Susan's recovery was smooth, apart from a frozen shoulder which she developed. This was treated at a later stage by a capsulotomy. We met approximately eight months after Susan had had the mastectomy, and three weeks after the capsulotomy operation. She was feeling well and started to volunteer in a cancer research fund shop. About six months after our meeting Susan was back at work in her studio as a beauty therapist.

Susan was a cheerful and lively person. Her attitude to life shown through the interview was a positive and optimistic one. The diagnosis of breast cancer shocked her at first, but quickly Susan pulled herself together and realised that there was a lot that she could do to help herself. She decided to keep herself occupied and thus prevent herself from sitting and thinking about the illness all the time. She stayed in touch with old friends as well as with new ones she had met at the hospital and who gave her an opportunity to talk and share experiences and emotions concerning the illness. She did not perceive herself as ill because her general health was good and therefore felt quite well throughout her treatment process.

RUTH

Ruth was 61 years old, married with four children (three daughters and one son), who had all left home. Her son was serving in the army and was still coming home regularly. Ruth had worked for many years in the Social Security Department, but had been retired for just over a year. She had also been doing voluntary work as a Samaritan for about ten years.

A letter Ruth received from her G.P., inviting her to go for a check-up at the mobile breast screening unit, made her go for a mammography. After

the mammography was done it was diagnosed that she had a malignant lump. It was too small, however, to have been felt by a manual examination. At this stage an appointment was made for Ruth to go to a specialised unit for further investigations. In the hospital a Fine Needle Aspiration (FNA) was done and this confirmed a malignant tumour. Ruth was told that she would probably not have noticed the lump herself for perhaps another five years. The treatment that was suggested to Ruth was to have a lumpectomy done with a follow-up treatment of radiotherapy.

The operation was done. Unfortunately, ten days later, Ruth developed a haematoma at the operation site. It was decided to open and drain the haematoma and daily wound dressings were carried out. Ruth lived rather far away from the hospital, but she still preferred to visit every day and have the treatment done there, and not at her local G.P.'s surgery. She felt more confident at the hospital. Ruth and her family had moved to a new home a few months earlier, and therefore the local surgery was new to her and she was unfamiliar with the staff.

Our meeting took place about six weeks after the operation. Ruth was still having a simple dressing to the wound although it had almost healed. On the day we met Ruth was due to go to the hospital to discuss with the staff of the Radiology Department the beginning of her radiotherapy treatment. She thought that they would not suggest starting the radiotherapy treatment immediately because the wound was still slightly sore.

The importance of radiotherapy for early stage breast cancer was, and still is, medically questioned. Therefore, there was a trial going on at the time to examine the importance of the treatment. Ruth was offered the choice to participate in the trial. If she opted to take part she would be randomly selected either to have the radiotherapy or not. Being a medically oriented and health conscious person who believed in research, Ruth decided to join the trial. Ruth had the support of her husband, who worked as a health physicist in the area of radiation protection, to join the trial. She was selected to have the radiotherapy.

SOPHIE

Sophie was the youngest woman interviewed. She was 37 years of age, married and had two small girls. It should be mentioned that Sophie made the effort to come to the interview from a town quite far away south of Edinburgh in the Scottish Borders. Sophie worked part time at a local factory.

Sophie discovered a lump in her breast about ten weeks before our meeting and was referred to a specialised unit by her G.P. After an FNA was done the decision concerning treatment was made by the doctors. Sophie understood she needed a mastectomy done plus six sessions of chemotherapy. During the discussion of her treatment the choice that was given to Sophie was either to have most of the chemotherapy before the surgery or to have the surgery first and then the chemotherapy, the latter being the more conventional practice. Sophie opted to have the chemotherapy first, since she understood from the doctor that in having it that way there was nothing to lose but perhaps something to gain. The doctor that told Sophie about this trial stressed, as Sophie recalled it, that this way of treatment showed itself so far to be the better one.

When we met, Sophie had already had two chemotherapy treatments which produced the positive effect of reducing the size of the lump dramatically. She was to have two chemotherapy sessions before the mastectomy operation and two sessions afterwards. Her exposure to chemotherapy was then fresh and still being experienced. She had lost her hair after the first chemotherapy session, and talked about how difficult that was. Sophie expressed some concern about the experience of her decision-making. These concerns were mainly related to the limited time, the lack of privacy and quietness in which to make the decision, and on the other hand the great loneliness involved.

ANGELA

Angela, a 59 years old lady, was single and had no children. She found a lump in her breast while on holiday, at the end of 1990. When she returned from the holiday her doctor referred her to the specialised unit.

The tests there confirmed a cancerous tumour in the left breast, and because of its relatively large size (over four centimetres) a mastectomy had to be done. No options were given to Angela concerning the surgery.

The only point where Angela felt involved in decisions regarding her treatment was related to her breast reconstruction. Angela opted to have a tissue expander put in at the initial operation. She thought that not much information or explanation was given to her about the reconstruction options.

The reconstruction was a rather traumatic experience for Angela. After a few months when the injections of fluid were almost completed an infection set in. The pain and discomfort associated with the infection were awful. The expander had to be removed and so the reconstruction lost. After the infection was cured, the doctors were willing to insert a new expander and repeat the reconstruction. The choice of whether to proceed was left to Angela. She decided she would give it another chance. The motives behind this decision, as she described them, were that it was only fair to give the doctors another opportunity to do the reconstruction. She wanted to be helpful and cooperative with the doctors. Perhaps it was related to a sense of gratitude she had, or perhaps she felt it was expected of her and that she would let them down if she did not agree to have a new expander put in.

The mastectomy operation did not frighten Angela, and she thought that having the breast removed would give her peace of mind concerning the possible recurrence of the cancer. On the other hand, having herself contradicting views, she said that if she had the choice she would have opted for a lumpectomy. Preserving the breast was highly important she thought, and for her even more so since she loved going on holiday and sun-bathing. The reconstruction was therefore important for Angela.

Since Angela had no family and was living alone, she presented herself as an independent woman with little need for help. The experience of having breast cancer was probably the first time she did need some sort of support. Her main support came from a close friend and some of her cousins and their families. Susan (interview 3), a friend she met at the

hospital, also was of special support, mainly since they shared the breast cancer experience. Angela was content with the form of support she had and in that respect felt in need of nothing more.

Even when Angela did have to make up her mind what she wanted, she did not seek any help or advice from anyone. She did feel though, that more information regarding the risks associated and the complications that might occur with the reconstruction should have been given to her.

LUCY

Lucy was a 50 years old married woman with two grown-up children. Lucy worked as a print finisher and talked with great enthusiasm of her work.

Lucy's breast cancer was discovered in a preventive breast screening to which she was referred by her G.P. She was approaching the age of 50, at which a first mammogramphy is advised for women who are not known to have any risk factors. Consequently a lumpectomy was performed.

The pathological examination following the lumpectomy was positive, and it was only then that the 'real' information had to be taken in and a decision concerning further treatment had to be made. Lucy was told that she might need radium treatment, but after the axillary lymph nodes were found to be clear this proved to be unnecessary. Lucy was put on oral Tamoxifen therapy, one tablet a day for five years, to prevent the recurrence of the tumour. At this point the doctor explained to Lucy the uncertainty of the results and the reason for his view that she might be better off having a mastectomy done. Lucy decided to go along with the suggestion. The operation was done about ten days before our meeting. A tissue expander was put in during the mastectomy operation, and when we met Lucy was just starting to go for the regular weekly injection of the fluid into the expander. Lucy seemed to have recovered well from the operation and was back home to normal activity, although slightly more tired and still off work.

I met Lucy at her home shortly after her return from the hospital. All the experience of the illness was still very fresh in Lucy's mind, which made

our conversation very interesting. The reconstruction has not yet started and she was to return to the hospital for the fluid injections.

The interview concentrated mainly on the process of decision-making that Lucy faced before finally opting for mastectomy. She described in detail this decision and the factors that had led her to agree to the operation. It seemed that Lucy's mind was quite clear, and she knew from the very beginning that she would feel more secure having had a mastectomy done. She saw it as extreme a choice as between living and dying. The idea of a mastectomy was not a shock for Lucy, and she had had the idea of it in the back of her mind even before the options were presented to her.

ROSE

Rose was 52 years old, married with two grown-up daughters. She had worked in the past as a technician in an x-ray department of a general hospital. At the time when we met Rose was not working. She was very expressive in her speech and showed a great deal of openness and sensitivity.

Rose first noticed a change in her breast when she was helping at a video shop. She felt her bra tight and uncomfortable. She thought that it had to do with reaching to the top shelves. A week later she discovered a distinct lump and went immediately to see the doctor. She was referred to the specialised unit and a small tumour in the lower inner right breast was confirmed. The routine staging examinations were performed and no secondary tumours were found. Rose was asked to come in for a lumpectomy operation with the removal of only a few lymph glands. However, all her axillary lymph nodes were unilaterally removed. This was done as part of a study examining whether having a total removal of the glands has an effect on the treatment outcome. As Rose understood it, she was not asked if she wanted to join that trial, she was just told that all the glands would be taken out. The immediate implication of the resection of all the lymph glands was a prolongation of her hospitalisation from three to seven days.

Concerning the rest of the treatment, Rose was given a choice between adjuvant therapy of radiotherapy and chemotherapy. This was also as part of a trial that was going on at the hospital at that time. The presentation of option shocked Rose, since she did not think she would need chemotherapy at all, and suddenly it was given to her as an optional treatment.

Rose was strong and decisive in her refusal of chemotherapy. She therefore decided not to join that trial and opted to have the usual radiotherapy treatment. At the beginning she felt a bit guilty about not giving consent to enter the trial. After talking to the counsellor, however, who reassured her that they could do without her in the trial, and realising that she had already been a part of a trial relating to the lymph nodes, she felt better and less guilty. Rose thought that the chemotherapy would make her feel ill and sick and she could not deal with that. Her family needed her to be fit and in good shape. She was the one who took control and responsibility for planning the family's life, and therefore she could not afford to be unwell. There was no one to take over her role as a mother and wife which she so much identified with.

We met three months after Rose's initial confrontation with the diagnosis of cancer. Rose had had a lumpectomy a few years earlier for a benign breast lump, so the procedure did not frighten her. However, she expressed some concern about the radiotherapy.

SANDRA

Sandra was 56 years old, married with two sons, and worked as an audio-typist. She was a health conscious person. She visited her G.P. once a month for a general health check-up. On one of the visits her doctor suggested mammography. Sandra, who described herself as being fond of medical examinations which confirmed she was in good health, went for the mammography test. At first she was told that everything was fine, but later that week she was asked to come for a re-check since something in the mammogram was unclear. At that point a suspicious lump was found and Sandra was referred to the specialised unit where a wide local excision was performed.

Sandra was then given options regarding the adjuvant treatment. The options that were presented to her were whether to opt for radiotherapy or a hormonal therapy - the Tamoxifen tablets. The options became more complicated when Sandra was told that she could also decide to have no further treatment, or have both the treatments. In the face of these four options Sandra became confused. How could she decide and who was going to help her make that decision?

Sandra didn't know anybody who was on Tamoxifen tablets that could give her advice or from whom she could learn about the treatment. One thing that she knew very well was that she had to have some sort of treatment. She was frightened that if she didn't have any treatment at all she would sit and blame herself if there was a recurrence of the cancer.

It was the family doctor that Sandra turned to for advice, and he said that she should opt for the hormonal therapy. This was a strong reassurance for Sandra who didn't want to have the radiotherapy. The radiotherapy frightened Sandra and it was really what she wanted to hear, that she would be fine by just taking the Tamoxifen tablets. She felt that she had done something active about her treatment and had not just left it untreated.

Sandra came to our meeting one hour late. This was perhaps the first sign that she found it difficult to talk about the illness and her experiences. The interview was probably the most difficult one in the sense that Sandra talked very little and I found myself having to ask many leading questions. This interview was also the shortest and lasted one hour. Sandra talked slowly and softly. It was about six months after Sandra was diagnosed as having breast cancer that we met, but the trauma she experienced could still be felt. She remembered the decisions she had to make concerning the treatment as particularly difficult and stressful. During the interview she was also anxious to get reassurance from me, asking several times whether I thought she had chosen the right treatment, and if I knew other women who had faced similar decisions. On the other hand she said she was confident about the Tamoxifen tablets and had faith in her doctor who had encouraged her to opt for that form of treatment. Sandra was still in a state of confusion.

LYNN

It was about two months after her mastectomy operation that I met Lynn at her home. She was a 50 years old teacher who looked young for her age. Lynn had been divorced for nine years. Her only son, aged thirteen, lived with her. Lynn perceived of herself as a single parent with all that is related to it, and talked about the difficulties involved. She had just started building up a relationship with a divorced man when the breast cancer was 'landed' on her.

One day, about eight months prior to our meeting, Lynn found a lump in her breast. She waited a few weeks and then went to see her G.P. who referred her to the hospital for a mammography. The tests confirmed that she had a malignant tumour and she was told that she would need to have a lumpectomy operation done. After the lumpectomy Lynn had the option of joining a medical trial for the adjuvant treatment. Lynn decided to enter the trial and was selected to have two chemotherapy sessions, then one local radiotherapy treatment, followed by four more chemotherapy sessions. The decision to enter the trial was not difficult since Lynn felt that she wanted to be as helpful as possible. Lynn had the treatments, but had been one of the unlucky ones where the chemotherapy did not have the positive affect of destroying the cancer. About a month after the last chemotherapy session she discovered another lump and was told that a mastectomy was necessary. A spread of the initial cancer, or a recurrence, is a medical indication to proceed to mastectomy. There were no options given to Lynn at that stage. A mastectomy was then performed. We met about two months after the operation and Lynn was doing well, still off work but already talking about going back to teaching, which she missed so much.

As for decision-making, not many options were given to Lynn. In the initial phase Lynn was told that a lumpectomy followed by adjuvant therapy would be a suitable treatment for her cancer, and that she didn't need a mastectomy. After the second lump appeared she was told that it had to be a mastectomy because of the recurrence. Again, no option was given to Lynn. Lynn made it clear that the mastectomy itself did not bother her. It probably would have been her choice had she been given the

option of a mastectomy initially. If this had happened then that might have saved her all the agony of going in again for a mastectomy at a later stage. However, Lynn expressed in the interview no regrets about the course of treatment she received and was confident in the doctors and the therapy she had had. It was the belief that the doctors would make her well that led Lynn to consent to the treatment and follow the doctor's recommendations. It was this faith that also gave her the energy to go on with her life in such a positive way.

Demographic and Treatment Data on the Women

This section summarises the main data on the respondents of the main study in a comparative manner. Table 4 lists the personal condition of the women, and table 5 outlines their relevant medical history. All women were in their first year after diagnosis and initial treatment and had completed the course of treatment when we met, unless otherwise stated.

Table No. 4 - **General Demographic Data**

Name	Age (years)	Marital Status	Children	Work
Jill	41	Married	1 Son	Nurse auxiliary
Mandy	60	Married	3 Sons	Shop assistant
Susan	42	Single	----------	Beauty therapist
Ruth	61	Married	3 Daughters 1 Son	Social security officer
Sophie	37	Married	2 Daughters	Factory worker
Angela	59	Single	----------	Housing officer
Lucy	50	Married	2 Sons	Print finisher
Rose	52	Married	2 Daughters	X-ray technician
Sandra	56	Married	2 Sons	Audio typist
Lynn	50	Divorced	1 Son	Teacher
	Average: 50.8 Range: 37-61	Married - 7 Single - 2 Divorced - 1	4 Children - 1 3 Children - 1 2 Children - 4 1 Child - 2 0 Children - 2	

Table no. 5 - **Data on Treatment (at the time of interview)**

Name	Time since diagnosis	Surgery	Adjuvant treatment	Reconstruction	Future Treatment
Jill	10 weeks	Mastectomy + Ovarectomy	----------	Tissue expander	
Mandy	6 Weeks	Mastectomy	Tamoxifen	----------	
Susan	8 Months	Mastectomy+ Capsulotomy	Tamoxifen	Flap	
Ruth	8 Weeks	Lumpectomy	Radio-therapy	----------	Radio-therapy
Sophie	10 weeks	Mastectomy	Chemo-therapy	----------	Mastectomy
Angela	11 Weeks	Mastectomy	----------	Tissue expander	
Lucy	6 Weeks	Lumpectomy+ Mastectomy	Tamoxifen	Tissue expander	
Rose	3 Months	Lumpectomy	Radio-therapy	----------	Radio-therapy
Sandra	6 Months	Lumpectomy	Tamoxifen	----------	
Lynn	6 Months	Lumpectomy+ Mastectomy	Chemo-therapy	----------	

The Nurse Counsellors and their Work

Breast care nursing as a specialised service is a relatively new discipline in Scotland. The first breast care nurse counsellor was appointed to her job in 1981 - some twelve years back. She was appointed by the medical Professor who opened the breast care unit in Edinburgh. A few years later when another Professor from Edinburgh moved up to Aberdeen to open his own practice in breast care, he also introduced the idea of nurse counselling. Two nurse counsellors, therefore, were appointed in 1986 in Aberdeen. They were based at a large community health center which is close to the main hospital of Aberdeen. Next, a post for a stoma and breast care nurse was established in Falkirk and District Royal Infirmary. In West Lothian, a community based nurse specialising in breast care was also appointed in 1987, and was attached to St. John's Hospital, Livingston. Further developments took place in 1992, when a post was given to a nurse to specialise in breast care in Kirkcaldy's Victoria Hospital, and a third nurse joined the Aberdeen 'team' of two nurse counsellors.

Seven nurse counsellors working in breast care in various areas of Scotland were interviewed in this study. The type of work that each one of them was engaged in was different, although some of them held the same job title. One of these nurses was also employed as a stoma care nurse, and breast cancer was only one aspect of her work. The other six worked primarily in the area of breast cancer. However, only one of them actually used the word counsellor when defining her job. The others were reluctant to call themselves counsellors and said that they did not have enough training in counselling to justify such a title.

Most of the nurses saw the practical, rather than the emotional, aspect of care as dominating their work. As an example, fitting the breast prosthesis was done by these nurses. Only one nurse was not involved in practical care and saw herself as a counsellor per-se, mainly providing emotional and psychological support to patients and their families. The type of work the nurses were involved in depended largely on the setting where they worked and the facilities available there.

Three of the nurses were hospital based, whereas four of them worked predominantly in the community. One of the nurses stressed in the interview that she was based in the community and that she followed breast cancer patients from diagnosis to death within their natural environment. The nurses that worked mainly in the hospital, referred breast cancer patients, at the time of discharge home, to the community nurses.

Three of the nurses worked together as a team at a main health centre in a large Scottish town. They were all nurses with a background either in community/district nursing or health visiting. Although they were based in a town, their work covered a whole large rural area of Scotland. This meant that at times they had to travel a long distance (up to a hundred miles) in order to visit a woman at home. Home visits were a major part of their work. They all stressed the importance of a background in community nursing as a base for their work.

As for their education, all the seven nurses were RGNs and had some form of post basic training. Three had special training in community nursing, and one was a qualified health visitor. One of the nurse counsellors was a nurse manager before she took on her present post. Another was a specialist in breast prosthesis fitting, and therefore was already familiar with the area of breast cancer when she started her present work. Only one nurse had actual experience and training in Oncology - she worked at the Marsden Hospital in London for a few years, and did the English National Board course in oncology nursing.

None of the nurses had a recognised qualification in counselling. Most of them attended short local counselling courses, but these were not equivalent to any diploma or certificate courses. Only two of the nurses did the Manchester specialised oncology counselling workshops offered by Maguire and Faulkner. One of them went to the Marsden Hospital in London to do the breast care nursing training programme.

In the following chapters the nurse counsellors will be referred to as NC 1, NC 2 etc. This is in order to differentiate them from the women who were given personal fictitious names. For the purpose of writing, there will also

be a general reference to the **nurse counsellors**, distinguishing them from the **women** with breast cancer. This, however, does not suggest of course that the nurse counsellors are not women themselves, with all that this may imply.

Summary

In this chapter the ten women interviewed have been introduced. Each woman involved had a different story related to her breast cancer diagnosis and treatment. The first important conclusion that can be drawn from these specific 'cases' is that there is no one 'breast cancer story', but many common factors to the decision-making process. It is individual women that I have listened to, and each one of them presented a different phenomenal world concerning her illness.

Most of the women (seven out of ten) discovered the breast lump themselves and then went to consult their own G.P. In the remaining three women the lump was found during a screening mammography. The general diagnosis of each woman was primary breast cancer, but each manifested different clinical symptoms. These differences related to the size and the location of the lump in the breast, whether or not the lymph nodes were affected, and the general health of the woman. Primary breast cancer can therefore be seen as an 'umbrella' diagnosis for various specific clinical presentations of malignant breast lumps which are found at an early stage. The treatments ranged from a simple surgical removal of the breast lump to a total removal of the breast - the mastectomy, and from no adjuvant therapy, to radiotherapy, hormonal therapy and chemotherapy as an additional systemic treatment. Some of these women had a combination of these different treatment modalities.

There were, however, a few points which related to their history of breast cancer that were common to all the women. These were:
- A diagnosis of breast cancer within the year before interview.
- Treatment at the same specialist breast cancer unit.
- Having faced a situation of choice relating to their treatment for primary breast cancer.

As can be seen from the situations described, the decisions each woman had to make concerning her treatment were different. The information given to each woman was different, and the resources for support each of them had for dealing with these decisions varied. Their coping ability had to do with internal factors, their personality, and with external factors such as the people around them. Some women received a great deal of support from their close family or friends. Others got most of their support from the health care team, mainly from the specialist breast care nurse counsellor. All the women had an opportunity to sit and talk to the counsellor. Indeed, she had some part in the experience of decision-making in one way or another.

In addition to the women, seven nurses working as counsellors in breast care were interviewed. Most of them, however, did not use the word counsellor when defining their job, since they felt they did not have the appropriate training. The nurses worked in various parts of Scotland. Some were community based, whereas others were located at a hospital. In this chapter these nurses were described as a group and not as individuals, in order to ensure confidentiality.

Chapter VII:

THE DECISION-MAKING EXPERIENCES

Introduction

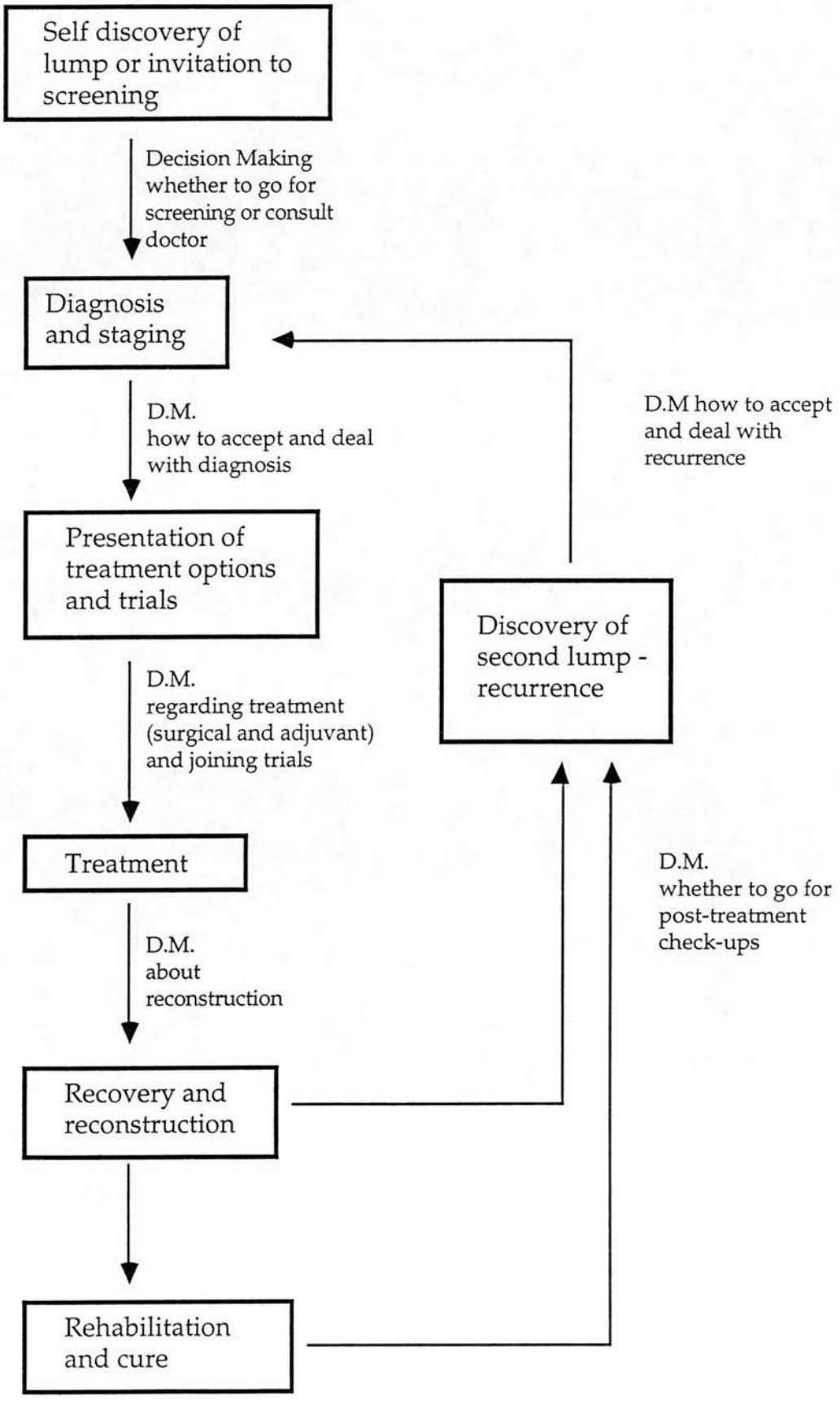
In this chapter an analysis of the respondants' accounts of the decision-making experiences is given. The chapter begins with a general description of the phenomenon of decision-making with which all the women were faced. Then, the themes mentioned by the women and the nurse counsellors, which relate to the participation in the decision-making about treatment, are explored. The themes demonstrate a process which consists of three different constructions of social realities: the woman and her Self-World, the relationship and interaction with the medical team, namely the doctor, and finally, the importance of the available network of support. Some extracts from general and professional literature, that were found to add to the understanding of a certain theme, are incorporated.

The Decision-Making Experience in General

The common experience that the women who were interviewed shared was having gone through a decision-making process regarding their treatment for primary breast cancer. Each of the women, however, faced a different choice, at a different point of her treatment. Breast cancer may be seen as a continuum - a process which begins with the discovery of a lump, or attendence for screening, and which ends with cure, remission or recurrence. In the case of recurrence, the process may be seen as a circle - returning to the beginning to the stage of diagnosis and treatment. There are many points along the 'breast cancer continuum' where the woman may be involved in decisions regarding her treatment. This is illustrated in Figure 2. The ten women, and some of the women in the 'Reach for Recovery' group could be placed at different points on that continuum because of the choices they had had to make.

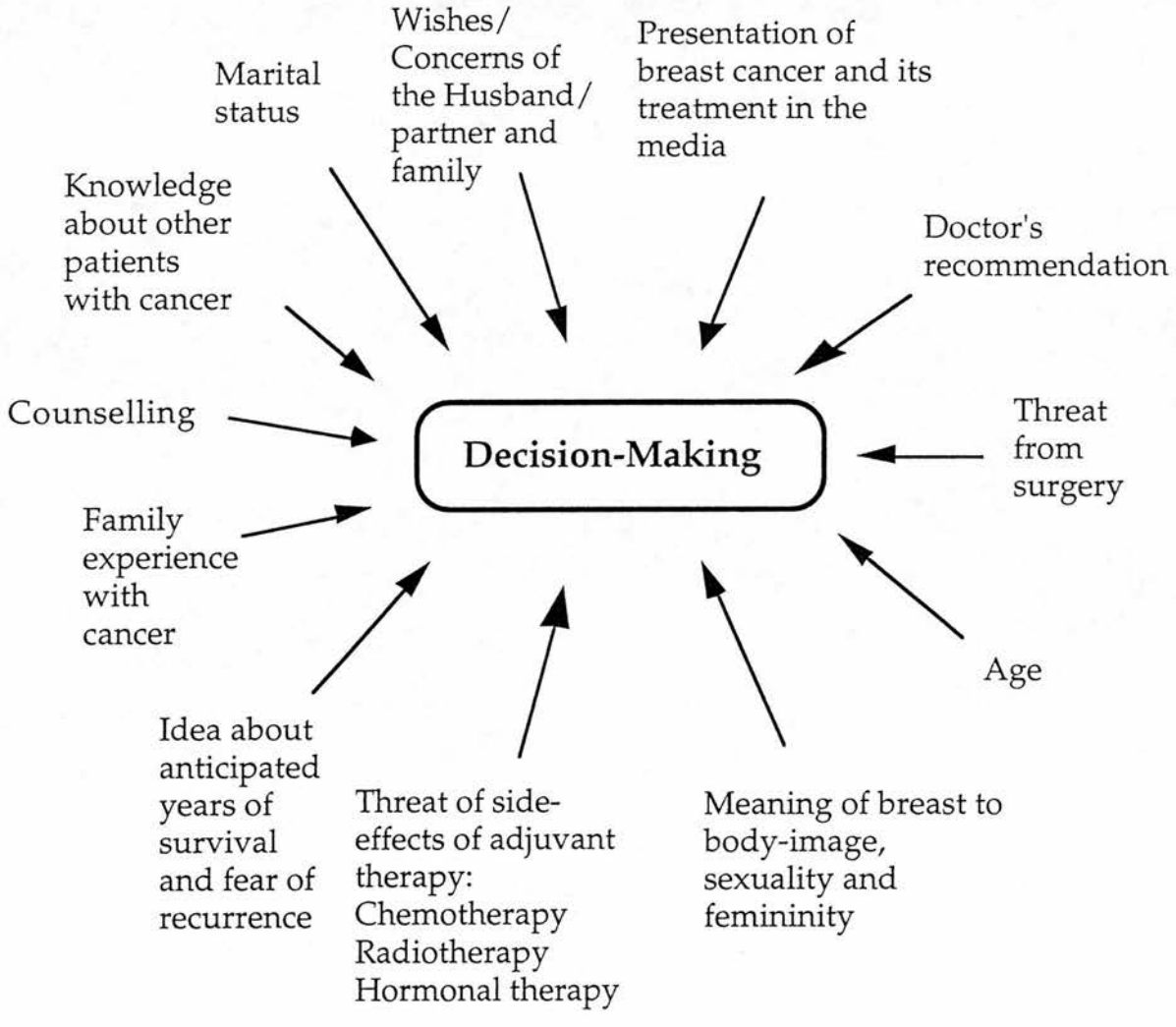
The women and the nurse counsellors described many factors as influencing the choices. A long list was developed which ranged from internal factors such as body-image feelings and the threat of losing a breast, to external factors which related to other people such as family and friends, the doctor, and even the presentation of the topic in the media.

Figure 2: Decision-Making Points Along the Breast Cancer Continuum



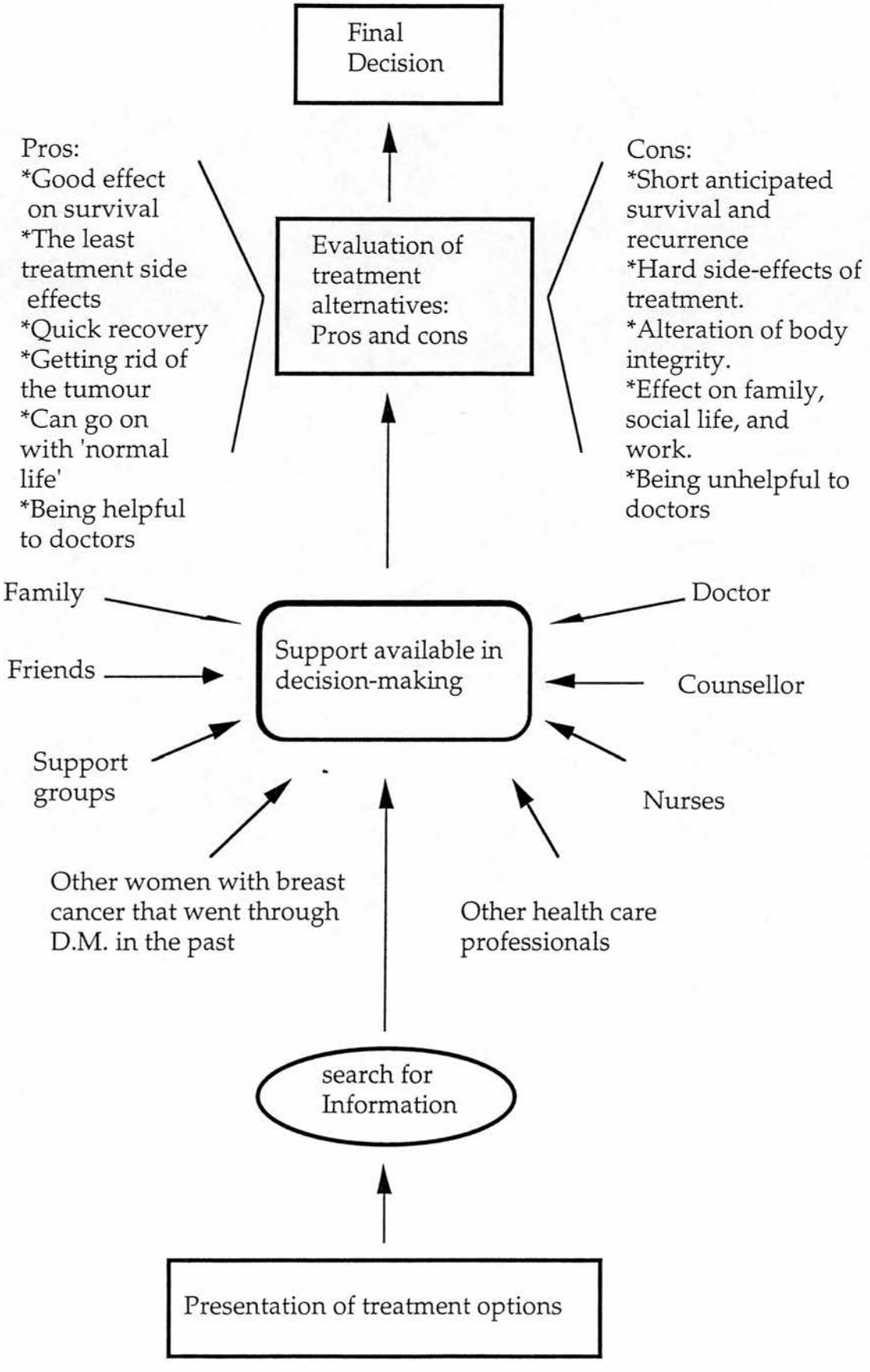
The variety of these influencing factors is illustrated in Figure 3, where the woman making the decision is placed in the centre. From their account of the influencing factors, it was clear that only a few factors played a part for a specific woman in a particular situation.

Figure 3: Factors Influencing Decision-Making



The decision-making process used by these women followed, for the most part, a straight forward pattern, starting with the presentation of options by the medical staff. There then followed some search for information. At that point the women made use of the support available to them for helping them to make the decision. To their subjective perception, an evaluation of the treatment options was then conducted, examining the pros and cons of each alternative. The pros related to the potential good effect of the treatment or the anticipated survival, the treatment with the least side-effects, quick recovery, getting rid of the tumour, and the fact that life could go on as usual. The cons, however, were considered if there were no side effects of the treatments, alteration of body integrity, and the effect the treatment might have on the family, social life, and work. However, in reality, nine of the ten women primarily followed one consideration once hospitalised: to please the medical team and 'be helpful'. After this evaluation was carried out, the final decision was made. This simplified decision-making process is illustrated in Figure 4. The specific themes, that were isolated from the narratives provided by the interviews, will be introduced in the following sections.

Figure 4: The Simplified Decision-Making Process



The Woman and her Self-World

A woman who is diagnosed with breast cancer and decision-making, is faced with an image of her Self-World. It is the woman herself and her inner world that is the reality described. Various themes identify this concept. **Being alone and feeling lonely** is one. **The burden of making a choice** is another. More themes are related to the woman's **personality and age**, and her idea of **the concept of health**, as affected by her breast cancer.

Another issue looks at the breasts as **a symbol of femininity and sexuality**. This provides the connection between the inner world of self, which comprises of feelings and emotions, and the physical being, in the context of breast cancer. The powerful influence of the threat of cancer and death over feelings of feminine identity, is described by the theme **'just want it away'**.

Being Alone and Feeling Lonely

The women expressed during the interviews the feeling that they were very much alone at the time of decision-making. They said in a variety of ways that 'there is no one that can make the decision for you, and as much support and help as you might have, you are still left on your own to make the choice'. Kfir and Slevin (1991) discussed in their book on Crisis Intervention the difference between **being alone** and **feeling lonely**. They said that very often we confuse the two, and regard both of them as positions that should be avoided. In being alone, they argued, there is only one person who is at the centre of his universe, and there can be no other, as no circle can have more than one centre. That person is I, only I and I alone. Being alone is reality, whether we like it or not, whether we run away from it or not, whether we are aware of it or not. We can choose to be afraid of it, deny it or make peace with it. That is I. My being alone, or rather my uniqueness, does not isolate me, rather, it distinguishes me.

Loneliness, on the other hand is a feeling that possesses us when we have no actual or spiritual communication with others. When by force of circumstances or by self-isolation, inferiority, feelings of competitiveness or fear, if we are not in touch with even one other person, this agonising

feeling of loneliness takes over. It is essential for us to distinguish being alone from loneliness, they say, because being alone is the fundamental characteristic of life itself. It will always be there and there is no point fighting it; rather, we must learn to accept it and even like it. Being alone can turn out to be very positive, a strength, once we have come to terms with it. If we confuse loneliness and being alone we will spend our lives in the frustrating attempt to drag another person to the centre of our circle to share it with us (Kfir and Slevin, 1991).

In light of these arguments I would like to refer to Sophie who talked about being alone during the decision-making about her treatment. Moreover, Sophie described the struggle between the wish to be alone and the difficult feeling of loneliness.

> *I thought 'how I wanted to be on* ***my own*** *and just try to come to terms with it'...*
>
> *I just wanted to be on* ***my own****, quiet and somewhere... (Sophie)*

Sophie felt that she had to cope with everything alone and that the decision about her treatment was also left to herself. That was when loneliness took over.

> *But the actual decision - it was* ***mine****, you know,* ***completely mine.***
>
> *I really do feel that a lot of the time it's* ***just me*** *that has to cope with it... (Sophie)*

Sophie was a wife and a mother and as such felt a great deal of responsibility for the family's life, which she could not share with anybody. She first had to cope with things alone, before talking about them with her husband. The same held true concerning her illness and the decisions about treatment which she had to make.

> *...but I felt that I had to come to terms with it* ***myself*** *before I could tell him [my husband], you know, it is sheer panic and... I have always been the stronger one, I have always felt that I have got to deal with it first and then decide how I am going to tell him and*

*then see how he copes, you know, that's the way I thought: 'it has to be **me** that has to cope with it first'. (Sophie)*

The feeling of loneliness is especially strong when things go wrong, she said:

*I wish there was somebody to just pop in to and say 'I am feeling very low today', but there isn't anybody... When things are going well like they are this week, good results, I am lucky that way, because if things weren't going well I don't know what I would do because **I haven't really got anybody** that I could lean on. (Sophie)*

It seems that Sophie acknowledged and perhaps even liked being alone - she needed to be by herself. However, she found the feeling of loneliness a painful thing to deal with.

Sandra also talked at length about the fact that you are all on your own to make the decision, no one can advise you, or make the decision for you. She seemed to have been searching for someone to put in the centre of her circle who could make the decisions for her. Even her husband could not be that person. She found it difficult to be left alone with four options of treatment, having to choose one, as described earlier.

*Well, I asked my husband 'what should I do?' but he didn't really know, he said 'well, that is really **up to you**, I couldn't advise you on that'. (Sandra)*

This is how Sandra described the fact that she had no one to talk things over with, which meant feeling lonely.

Yes, I was a bit shocked when I was told the diagnosis, it felt rather... I was shaking really, and there wasn't anybody waiting for me when I came out [of the doctor's] either. The person, the friend that came with me she had to go, so... but I phoned my husband and asked him to come and collect me, because it was just close to his finishing time [at work], and I told him [the diagnosis] on the way home in the car. But he is very quiet - he doesn't say very much. So

*these were the times when I could have done with somebody to talk it over with,.. **I felt alone**... (Sandra)*

Lynn also talked about being alone and feeling lonely. She was divorced, her mother was old and ill, and her son was too young to share these things with. The new relationship with a divorced man she had just developed before the diagnosis of her cancer, was not yet secure enough to allow her to rely on it as a means of ameliorating the feeling of loneliness.

*...and in my case, I was very upset, felt very **alone**... (Lynn)*

Jill talked all through the interview about the good support she had from family and friends. However, she expressed the feeling that at the end of the day you are on your own:

*It might seem that there is someone there to help you with your fears, but you are **on your own** at the time. (Jill)*

Being alone is an existential aspect of human life and therefore as nurses there is nothing we can do to change it. We can only make the women aware of its nature. As long as women are given the possibility to choose their treatment, as is becoming increasingly common in breast cancer, they will feel alone. In relation to the feeling of loneliness, however, nursing can offer much support. Being with the woman at the time of decision-making, providing sound advice and through counselling, may help her to overcome what can be an extremely lonely experience. At the 'Reach for Recovery' discussion group an interaction between two women summarised this idea:

*- It takes time to get used to the idea and you've got to be given the chance to come to terms with things **yourself**, and whether it has to do with counselling or no counselling, no one can really do it for you.*

*- At the end of the day it's you, and you are on **your own**. (DG)*

The Burden of Making a Choice

The nurse counsellors in the research were united in the view that giving women the possibility to participate in the decision-making regarding their treatment may place an additional burden on the individual woman. In a sensitive manner, NC 2 expressed her idea:

> *But I feel quite honestly, this is a personal point, that I feel sometimes a choice or an option creates a dilemma for that woman... I said to one of the surgeons that I feel that it's putting the woman, sometimes, through a more traumatic, stressful situation that some women can't, I think, some women can't cope wth having a choice. (NC 2)*

A similar argument was provided by NC 3, who in addition offered an explanation as to why making a choice might be experienced as a burden:

> *A lot of people say they want the choice but I think it can be quite a big burden for a lot of people. I mean, I think it really is because what they want is somebody to say 'this is the way to go so that you will be 100%, never have problems in the future...' and you can't do that and so there isn't really a right or wrong choice and that for people is very difficult. So I think we can put quite a burden on people by giving them the choice. (NC 3)*

Furthermore, NC 1 explained who she thought are the women who will find the decision-making situation a particular burden.

> *...people who are alone, people who've recently had some sort of emotional upset like the death of somebody or a divorce or sometimes even moving house, all these sort of losses, are in a bit of a turmoil and may find the burden of making a decision about their treatment just too much for them. (NC 1)*

She continued by arguing that people who are living alone are most vulnerable:

> *And people* ***alone,*** *they're the ones who have the most difficulty in making decisions. (NC 1)*

From the women's point of view, Sandra seemed to have experienced the decision-making situation as extremely stressful and hard. She had a choice concerning the adjuvant treatment. She could opt to have radiotherapy, hormonal (Tamoxifen) therapy, neither treatment, or both treatments. Sandra was confused. On the one hand she did not want to have radiotherapy:

> *So I didn't know what to do really. I've heard so many different bad things about radiotherapy... (Sandra)*

But on the other hand Sandra felt that she had to actively participate in her treatment. Finally, taking the Tamoxifen tablets became Sandra's preferred choice.

> *...I thought 'well, I don't just want to do nothing at all, because if there will be a recurrence I might sit and blame myself: If only I had decided to do something'. (Sandra)*

Sandra found making the decision regarding her treatment a difficult thing. She appeared to experience a sharp conflict between her fear of illness and her fear of the therapy. However, her hesitations were also related to the fact that she had four options from which to choose, and possibly also to the fact that she had had a lumpectomy and did not feel secure enough that the cancer was eliminated.

> *Well, I can say that it is a very hard decision to make, I didn't know what would be the best...*
>
> *So this is why I have found it difficult...*
>
> *I had lots of decisions in my life to make, but that was a very difficult one. (Sandra)*

Not for all the women, however, was the choice of treatment a difficult experience, to the extent that was reported by Sandra. It seemed that the nurse counsellors had a somewhat more negative perspective of it than the women themselves. This could be explained by the nurse counsellors'

protective attitude toward the women. It is still important that the women are monitored for the stress and anxiety they may be experiencing in the decision-making situation.

Personality and Age

It is a well accepted concept in the psychological literature that personality type is associated with the development of, and coping with, cancer. In a simplified way, this view is often shared by the public. As a result, the woman with breast cancer may feel guilty and hopeless, blaming herself for the cancer which she now has. This is illustrated in the American play Purple Breasts that has explored this phenomenon. The main actress, a woman faced with a diagnosis of breast cancer, has a nightmare about the possible cause of her cancer being related to her personality traits. This is called the nightmare scene:

> *Doctor::* One hundred twenty-six thousand cases diagnosed so far this year...
>
> *Nightmare woman:* There is a strong correlation between the occurrence of cancer and the type of personality described as a "receiver repression"...
>
> *Doctor:* One hundred twenty-seven thousand cases so far...
>
> *Nightmare woman:* Melancholic women exhibiting internalized self-destructive drive toward using cancer as a passive form of suicide.
>
> *Doctor:* One hundred twenty-eight thousand cases now...
>
> *Nightmare woman:* These women display phobias, depressed personalities, repressed aggressiveness, denial, suppression, and inhibited motherhood.
>
> *Doctor:* One hundred and twenty-nine thousand cases now diagnosed...
>
> *Nightmare woman:* There is a strong tendency toward unresolved hostility directed at their mother...
>
> *Doctor:* One hundred and thirty thousand cases so far...

Nightmare woman: Repressed conflict in their lives resulting in depression of the immune system.

(Lindstrom, 1990, pp. 35-36)

This passage is an example as to the way women may be affected by these psychological research findings, or of the way they might be presented in the media.

The Simontons, in their book on the life-saving self-awareness techniques that they developed, conclude this topic by pointing out:

> We have found that explaining the psychological literature to cancer patients is a particularly sensitive task. If we make a statement that "research indicates that cancer patients have certain traits...", then many patients automatically assume the research says they personally have those traits. But statistical studies, by their nature, are broad generalizations that apply to groups, not necessarily to a particular individual. (Simonton et al., 1990, p.60)

At this point, I would therefore like to describe the views of the individual women in this research when they talked about their personality and its relation to the present illness. Most of the women saw themselves as having a strong, cheery nature and that they did not allow the cancer to 'put them down'. Indirectly, they commented about attitude to life, mood changes and certain personality traits.

Lucy described herself as a cheery person and said that the way one copes with the illness and treatments is all a matter of attitude.

> *I think everybody's feelings are different, some people really... I would imagine that some people must go hysterical. I wasn't like that, I think it just depends on your attitude, you know. I have always been 'happy go lucky', nothing really bothers me too much, I am easy going and... even in my work people say 'you are always laughing and giggling', it's just me, and I think that's what has helped me, but I think if I had been... maybe with a different attitude I may have been more... upset. (Lucy)*

Being able to talk about things was also important for Lucy. She said that being a talkative person might help.

> *I felt better since I spoke about it. I don't think I could have kept it to myself. If somebody said to me 'Oh, how are you?' and I would say 'I have been to the hospital, I had cancer, and I had the tumour cut out, and I had the breast [taken] off' And they would just look at me and say 'Oh...' but I says 'I am fine', and that's it, and before I could never say that. (Lucy)*

Lucy repeated a few times in the interview the idea that it is all a matter of attitude, the key word for her.

Susan also possessed this positive attitude. She said that she was never really 'down' or depressed and that she had a positive outlook on life, which helped her to cope with the cancer.

> *I wasn't depressed, not at all. There were some days when I thought 'why me? what have I done to deserve this?' But I cannot honestly say that there was a time when I really was searching out for somebody to really comfort me, you know. (Susan)*

Concerning the effect of age on the attitude to decision-making, two major things were mentioned by the women and the nurse counsellors. The women mainly talked about age-related attitude to the breast and its connection to the decision-making about treatment. This will be further discussed under the theme 'the breast as a symbol of femininity'. The nurse counsellors, however, talked more about the general attitude to participation in the choice of treatment, as related to age. They suggested that younger women were more likely to take an active part in the choice of treatment, whereas older women would tend to leave the choice of treatment to the medical team. Here are a few examples as to how the nurse counsellors understood the effect of age on the wish to participate in treatment decisions:

> *...ofter the elderly are not very happy to make decisions... They really like the doctors, in the main, to make the decisions for them. (NC 1)*

...younger women who have been well educated, I don't mean well educated from academically well educated. They're young, they've grown up with a peer group of people who are used to... they're not in awe of the doctors, they normally will ask questions and they will often make decisions themselves... (NC 1)

...it's sometimes the older generation who are not used to being given a choice in medical treatment anyway, and they say: 'well you make the decision for me' to the consultant, and will often ask the nurse specialist'what do you think?'... (NC 4)

I think younger women who are maybe more vocal anyway, more aware of choice, aware of what's on the media, they tend to want perhaps a little more choice than older women. (NC 4)

By being close to the patient, nurses are in a unique position to take personal characteristics and age into account when providing nursing care. Caring for a woman with breast cancer who is faced with difficult decisions with regard to her treatment should involve trying to understand her personality. Understanding personality means exploring who that woman is and what may influence her decision-making: her desires, aspirations, needs and values, in view of her age, cultural and familial backgrounds. Being open, lively and cheerful, as the women interviewed generally described themselves, may be a feature of the Scottish people, at least as it is expressed on the surface. It may also be characteristic of those who were prepared to take part in the research

The Health Concept

The concept of health is a complicated one. There are various definitions of health. These take into account physiological, psychological, social and cultural factors. In this section I would like to discuss the women's views concerning their general health and how it was affected by the diagnosis of breast cancer. Health is connected to self-perception and image, and therefore exploring the women's self understanding of their own health is of great importance. It is a subjective, rather than an objective concept.

In general, the women expressed the view that the breast cancer itself did not make them feel ill, or rather unhealthy. The idea of feeling ill was used more commonly with regard to the treatment, primarily

chemotherapy and extensive surgery. It should be noted though, that these women were diagnosed as having primary, early stage breast cancer.

Good general health is important for a quick recovery, said Susan. She did not feel ill and recovered well from a major operation which involved a mastectomy and an immediate flap reconstruction.

> *... and because I don't feel ill at all, my general* ***health*** *is very good... (Susan)*

If one is healthy, the possibility of fighting the cancer is much higher. This is where the self perception or attitude towards one's own health plays an important part. Rose was rather frightened at the beginning when she heard the diagnosis, and thought that having cancer meant dying. However, after a while she realised that since she was in good general health she had a high chance of being cured.

> *To me having cancer meant you died, you know, I didn't know anyone really who had cancer, and to me it meant that you died, I didn't realise that you could be cured, and then logically thinking back, I am not unintelligent, I have worked in a hospital, I knew it could be cured but the first thought was 'Oh dear, I am going to die, and I am fifty two', and then when I got over that I realised 'yes it can be cured' and I did stand a good chance - I was* ***healthy****... (Rose)*

For Rose to be healthy was very important in order for her to function well. As described earlier, Rose was facing a stressful situation at home and she felt that she needed to be healthy and well so that she could cope and be in full control. She decided not to have chemotherapy since she believed it would make her feel unhealthy. This is an example of the way that the perception of health may affect the actual choice of treatment. The family needed her to be well and healthy. Feeling unhealthy was therefore not related to the diagnosis of cancer as such, but rather to the related treatment.

Sandra was an example of a woman who was obsessed with her own health. For her it was extremely important to know that she was well and healthy.

Well, I visit my doctor maybe once a month or every six weeks, for a ***health*** *check-up, he keeps checking my weight and* ***general health****, you know. So in one of the visits he suggested a... how would I like to go for a mammogram? So I said 'right, I will go' I mean I like to go for smear tests and things, to see that I am fine. (Sandra)*

For Sandra being diagnosed as having breast cancer was devastating. She found our interview rather difficult and did not talk as much as the other women. During the interview Sandra seemed to be somehow distressed and was searching for reassurance from my side. This was interesting to note in the light of the fact that Sandra had "only" a lumpectomy done and had Tamoxifen tablets as her adjuvant treatment. One explanation for that might be Sandra's obsession with her health and the importance she gave that topic in her life. Another explanation was that she felt she did not do enough for her treatment, or rather for her health. However, it is possible that contrary to the other women, Sandra rather faced the truth of her disease and was unable to deceive herself concerning the prospects of her illness.

From a different perspective, Angela could not understand how she suddenly had this malignant tumour, since she always enjoyed good health.

I was never in hospital before I went into [the specialised unit], I have had very good ***health*** *and the fact that this was a cancerous tumour was... I could hardly believe it at the time. (Angela)*

Angela, therefore, perceived her cancer as something that came 'out of the blue' and destroyed her usual good health.

In a similar way one of the women in the 'Reach for Recovery' discussion group said that the thing that worried her about the cancer was the effect it might have on her general good health.

...it was the overall picture of my ***general health*** *and my future that I worried about... (DG)*

The way the diagnosis of breast cancer affects one's own perception of one's health is an interesting area to look at. From the words of the women it seems that having breast cancer did not in itself make them feel ill or unwell. However, some of the curative treatments were associated with feeling unhealthy, especially chemotherapy. This has to be kept in mind when the choice of treatment is to be discussed. For example, a woman who feels extremely unwell because of having the cancer in her body, may be more willing to have treatments that make her feel ill (e.g. losing weight, losing hair, becoming pale and anaemic etc.), whereas a woman who believes the cancer has been fully removed or does not substantially threaten her health will probably refuse to agree to any form of treatment that is associated with extreme discomfort.

The knowledge that metastases could have already started by the time of operation may be for some women the major factor in formulating their anticipation of their future medical prospects and their decisions on therapy. Nevertheless, it is interesting that in the present study the women generally appeared to conceive of physical discomfort as illness while disregarding the threat of cancer to their health if they had convincing evidence that all of their neoplastic tissues had been removed or they had suffered no direct discomfort from tumours. These misconceptions, when they exist, and the fears associated with them vary, however, from one woman to another.

As nurses we should explore these issues with the women who are faced with decisions regarding their treatment for breast cancer. Becoming familiar with the individual woman's attitude towards health and the way she perceives herself in relation to that concept may help us to help her cope with the crisis caused by having to make a decision. This insight may also assist the woman to understand herself better in relation to the illness and the decisions involved.

The Breast as a Symbol of Femininity

The female breasts are a symbol of femininity, sexual identity and are intrinsic to the body image. This is by nature a sensitive issue, and talking about it may cause embarrassment to some women. Breast cancer and

mastectomy are, therefore, particularly delicate topics. The women in this study were generally reserved in discussing these topics and therefore much of the data is of an indirect nature. In some of the interviews there was a restriction as to the degree to which the women were prepared to talk about their feelings concerning their illness and its treatment. Furthermore, talking about feelings toward the breast and the effect of breast cancer on sexuality, femininity and body image entailed in some way or another a discussion of their relationship with their partners. This was an extremely private matter for most of the women. However, I will give some examples and hope to provide an insight as to how this is related to the decision-making these women were faced with.

Mandy, who was 60 years old, said that having her breast removed did not bother her much. She continued to say that if she had been a young woman it might have been different. It is, therefore, a matter of age. She had the option of having a reconstruction done but she chose not to have it.

> *When it came to the bit of having the mastectomy done, it didn't bother me one little bit, I wasn't unhappy about having my breast removed. If I had been a younger woman, it might have affected me more psychologically than what it did, but then I got the option of having the build-up, you know, when you get the tissue expansion, but I wasn't ready for that. (Mandy)*

Lucy also said that a mastectomy was not a big issue for her. However, like Mandy, she realised that age might have influenced her. Lucy was 50 years old. She talked about the fact that it was a matter of attitude and said that if she had been younger, her attitude towards the loss of a breast might have been different.

> *I wonder if maybe my attitude would have been different if I was a younger woman? I mean there might have been a difference in my attitude, I might have said 'I am not going to do that, what I had done [mastectomy]' I don't know, I couldn't tell, maybe if you were thirty your attitude might be a different thing. (Lucy)*

Lucy suggested that keeping the breast might be more important at a younger than at an older age. This point is personal, since for many elderly women the breasts still play a vital part in their sexual lives and are most important in preserving a positive feminine body image.

For Lynn, fitting the prosthesis before going home after the mastectomy was a very personal matter that she found difficult to share with a stranger. Furthermore, she said that while for nurses such a personal relationship with the patient is enjoyable and rewarding, for the woman whose breast is discussed it is a very sensitive and private issue.

> *The girl that fitted me, she seemed to be proud in doing that... and she took me along to... and said: "Look, Mrs. L is looking good", and she made a wee joke there, they always make jokes, you know. I think the nurses actually enjoy this relationship, but for the woman it's very personal... going with your own body to somebody who says: "We'll put a little bit more puffing here... and a wee bit more up there.." and then you walk out with the bit they fitted for you... yes, it's really quite a difficult thing to cope with... (Lynn)*

For many women it is extremely difficult to look at the scar that is left after the mastectomy operation. Some of the women talked about that. They tried to avoid confronting it. In a Scottish play on breast cancer (And the Cow Jumped Over the Moon, Franceschild, 1990) there is a scene which illustrates this idea. Andrea, the apparently coping patient, tries to help Eloise who has not been out of bed since her operation and has not changed her night gown yet. Eloise is receiving chemotherapy and feeling sick. Andrea tries to make Eloise change her nightie and make her look better.

> Andrea: I don't wannae make love tae ye, Eloise! I just wannae change yer nightie!
>
> Eloise: (struggling maniacally with Andrea) No! Don't! It's ugly! It's ugly!
>
> In the struggle, Eloise nightie is ripped down the front. Andrea draws back as Eloise frantically holds the nightie together and curls up into a ball to protect herself.

Eloise: It's ugly! Don't look! Don't look! It's ugly!

Andrea: (After a moment, unbelieving) Ye've never seen it huv ye?

(Franceschild, 1990, p.33)

The effect of breast cancer and mastectomy on body image, and consequently on femininity and sexuality is an important issue that needs to be explored with the individual woman. Some women, however, may not wish to discuss these issues overtly. For those women who choose to be more covert in their attitude, these issues may still be crucial in determining their choice of treatment, and their general coping with the disease.

'Just Want it Away'

The majority of the women in the interviews, and also most of the women in the discussion group, expressed the wish to 'get rid' of the cancer. For the women who expressed this view, 'getting rid' of the cancer meant having a mastectomy. The nurse counsellors also thought that most women wanted to have a mastectomy in order to 'get rid' of the cancer. It seemed that the women still possessed the popular view that cancer is a regionally confined local spreading disease, rather than a systemic illness, spreading in the body through the blood and lymphatic systems. Because of this idea, the women believed that mastectomy would ensure complete removal of the cancer. This fitted well with the results of the Newcastle study (Wilson et al., 1988) which demonstrated that when given a choice, most women (two thirds) preferred to have a mastectomy done, rather than a lumpectomy followed by radiation.

Every woman interviewed in this study was motivated by the wish of 'getting rid' of the cancer. They were willing to 'sacrifice' their breast - the symbol of their femininity and sexual identity - for the sake of 'getting rid' of their cancer. If a particular woman did not actually have the choice of treatment regarding the extent of her breast operation, then this issue was discussed hypothetically. The nurse counsellors were also questioned about their experiences with women who had a choice regarding their

surgery. Their views in that area demonstrated their reality of being themselves both women and breast-care-nurse-counsellors.

Here are examples as to what the women said in relation to the topic of wanting to 'get rid' of the cancer.

> *My main concern of... you know after I had discovered I had a malignant tumour, all I was concerned was to* ***get rid of that malignant tumour****, and I wasn't caring what really... I mean, as long as they* ***got rid of it****. When it came to the bit of having a mastectomy done, it didn't bother me one little bit, I wasn't unhappy about having my breast removed...*
> *My own feelings were 'I had a cancer and if they could* ***take that cancer away*** *by taking my breast off, by all means the breast should be coming off, and it didn't bother me one little bit, it really didn't'. (Mandy)*
>
> *I think psychologically if you know they have done a mastectomy then you know that they have* ***taken everything away****, and your mind is more at rest. (Susan)*
>
> *I think many days, again psychologically, I would feel that if the whole thing [breast] was away then they must have* ***got it all****, if they just removed the lump I might still have had it [the cancer] in my body... I just wanted them to* ***remove the breast*** *- to* ***remove the tumour****... (Sophie)*
>
> *When it was confirmed, you know, that that's what it was and that I was going to have a mastectomy, I told [the counsellor] that I wanted this [the cancer]* ***rooted out****, you know, I didn't have any difficulty facing up to it [the mastectomy], if you like. (Angela)*
>
> *I mean that was all I was concerned that he would* ***get rid of the cancer****, and I was happy with that [the mastectomy]...*
> *... and he says [the surgeon] 'if you* ***take it away****' he says 'you will have peace of mind for the rest of your days, and that would be it'. So I felt that I'd rather have my peace of mind , so I was quite happy [with having a mastectomy done]. (Lucy)*

These are just a few examples from the individual interviews. In the discussion group the view that mastectomy was the safer way for 'getting rid' of the cancer was also the dominant thought. Here are two examples:

- I actually did have a choice. I was given a choice to have a lumpectomy or a mastectomy. I chose to have a mastectomy. I chose to have a mastectomy... I suppose my choice was a lumpectomy with radiotherapy or a mastectomy and no more treatment. And that was why my choice was done. I just wanted them to ***remove the cancer****, I couldn't care less whether I had one breast or two.*

- ... and it's just that you are so suspicious and you want to ***get totally rid of it****... as you say, it's cancer that you want to* ***get rid of****. (DG)*

This view instigates the suspicion that the common mistrust in lumpectomy arises from the fact that it is always associated with adjuvant therapy. If adjuvant therapy is necessary then there must still exist a possibility of remaining malignant tissue. Mastectomy and removal of axillary lymph nodes, on the other hand, is normally the final curative treatment. This is interpreted by the women as sound evidence for the effectiveness of mastectomy in totally eliminating cancer.

Although this was a common view, some of the women expressed a certain ambivalence on this issue. Susan was an example of that. She said throughout the interview that she did not mind having a mastectomy since it gave her reassurance that the cancer was gone and consequently peace of mind. However, when asked hypothetically what she would have chosen had she had the choice, she got slightly confused and gave a rather ambiguous answer:

... so I really don't know... if you would have said 'lumpectomy or mastectomy' I think I probably would have said 'lumpectomy' because no woman wants to lose her breast unless it's really really necessary! But, having said that, to lose my breast didn't really bother me, em... because as long as I was going to be well after this, em... but you know, I think lumpectomy would have been my choice... (Susan)

Mandy agreed to have the mastectomy in order to 'get rid' of the cancer and because radiotherapy (the additional treatment to lumpectomy) might be dangerous to her damaged heart. Otherwise, she said, she would have chosen the lumpectomy as her surgical treatment:

Em... It really... if they hadn't said there was a risk to my heart because of the radium and they told me to go home and think about it, em... I don't think I needed to have thought about it. If they had said to me there is no risk attached to having the radium treatment, I would have gone ahead with what they had suggested at first, having the tumour and the lump removed and five weeks of radium treatment and the tablets, and that's it. I wouldn't have needed a second thought. Probably I really didn't need to think about it because of the risk factors and that was the only reason I had said yes to mastectomy. There was no doubt in my mind that it had to be a mastectomy. But before that, if they said there was no risk at all I would have gone with just having the tumour away and the lymph glands. (Mandy)

This ambiguity in the attitude towards losing the breast is of no surprise. As Susan understood it: "No woman would want to lose her breast unless it is really really necessary". Whether it is really really necessary to 'sacrifice' the breast depends for every woman on her subjective interpretation of the situation. Lucy, for example, took on an extreme view of it being a choice between life and death. She got friendly with a young woman in the ward who needed to have a mastectomy done. That young woman wanted to refuse the mastectomy since she was frightened of it. Lucy got extremely concerned and told the woman that it was a choice between life and death: if she wanted to live she had to agree to have the mastectomy.

We did have a young girl in, she was getting a mastectomy done and felt very bad about it and almost refused it, and I said 'you have to look at it like that: do you want to live or do you want to die?' (Lucy)

From a different perspective, NC 4 understood that most women would react to the cancer rather than to the loss of the breast:

...their [the women's] reaction very much at first is to the cancer, not necessarily to the breast loss or possible breast loss. so their reaction is, in many cases, 'just take it off, take the cancer away'. (NC 4)

In a similar way NC 5 said:

...I'd say there's quite a good proportion of them [the women] that believe in just removing the breast...
Also, I feel that they don't want a long protracted treatment as well. 'Let's get on with it, get rid of it and get back to normal'. (NC 5)

It is of great importance for nurse counsellors to understand that, in general, women faced with a diagnosis of breast cancer may prefer to have their breast removed, and feel that the cancer is gone, than preserve their feminine identity in the form of keeping their breast. However, it clearly remains an extremely personal matter which needs to be explored with the individual woman.

The Relationship with the Doctor

The reality of the Self-World was 'disrupted' and 'invaded' by the relationship with the doctor. It became a dual social interaction which meant stepping outside the personal circle of being. The interaction with the doctor was the first social encounter the women were faced with when given the diagnosis and the options concerning treatment. In the following section the themes that describe this doctor-patient/woman relationship are further discussed and elaborated.

The Doctor Knows Best

Having faith in the doctor was a common attitude. When faced with choices regarding treatment, the women generally felt that the doctor knows best and therefore he should be the one to make the decisions. He was the one with the expertise. The nurse counsellors also mentioned in the interviews the idea that the doctors had a great impact on the women. Even the way the diagnosis was communicated by the doctors had a long term effect on the women's emotional coping. The fact that most doctors were male was also noted. This seemed to have some positive, as well as negative aspects. The positive part of it was related to the fact that it was important for the women at that stage to see a male figure that they could trust. The doctors in the specific unit seemed to have adopted a paternalistic, somewhat protective attitude towards the women, which made them develop a great deal of trust in them. For example, Lucy remembered saying to the surgeon "You are the man, you are the head man, what would you tell me to do?". The negative aspects stemmed from the idea that men could not **really** understand what a woman may feel when being confronted with such a feminine-related life-threatening situation. This was expressed by some women when they talked about the importance of having a female counsellor.

In Solzhenitsyn's Cancer Ward, Dontsova, one of the female doctors, discussed this issue. She was convinced that doctors should make decisions on behalf of their patients, and that this is an integral part of the practice of medicine. Without this responsibility, she believed, medicine would not exist. This is illustrated in the following conversation

Dontsova has with one of her patients, trying to persuade the woman to agree to have the radiotherapy treatment she was refusing.

> 'Why do you assume you have the right to decide for someone else? Don't you agree it's a terrifying right, one that rarely leads to good? You should be careful. No one's entitled to it, not even doctors.'
>
> 'But doctors *are* entitled to that right - doctors above all,' exclaimed Dontsova with deep conviction. By now she was really angry. 'Without that right there'd be no such thing as medicine!'
>
> (Solzhenitsyn, 1988, p.89)

Most of the women in this research were happy that the doctors made the decisions for them, especially in this specific situation. However, a few of the women were still in favour of the idea of participating in the choice of their treatment. Sophie made a distinction between 'big' decisions that should be made by the doctor and 'small' decisions that could be left to the woman.

> *So sometimes if it's a minor thing, I would say 'yes, you should be involved', but the actual treatment, I think you've got to say 'well,* ***I am in your hands****, you know more about it than me and I will do whatever you say...' So I do feel more* ***in their hands*** *and I don't have much say - I don't know whether I want much say, 'cause I feel it's too serious...*
>
> *Em... I had more* ***confidence in the doctors****, I feel I don't know enough so I have to have confidence in them and so if they would say 'yes, we feel it's better to have a mastectomy' even if I'd rather have the lumpectomy, you know... I was guided by them. It's hard to tell, but I would rather say 'keep the breast' but I feel surely they wouldn't just remove it if they didn't think it was necessary, so I feel maybe they have had more expertise. (Sophie)*

Doing what the doctor suggested was also Jill's attitude:

> *...but I mean I thought to myself 'if that's what they [the doctors] suggest I will just follow that... (Jill)*

Jill's decision to have the mastectomy was even clearer when it was not only one doctor that suggested this treatment, but three doctors:

> *On a Tuesday I had made my mind up about the first decision, but that was one doctor's decision, and then on the Wednesday morning when it was three doctor's decision, I just accepted that and said 'I will go along with what you think' I was quite happy about that. (Jill)*

For Mandy it was more than just following the doctor's recommendations. She thought that if you have faith in your doctor then you **must** do what he advises you:

> *I took [the doctor] advice. I have a lot of faith in that man and, em... I think if you've got* ***faith in the surgeon*** *then you must do what he tells you. (Mandy)*

Angela believed that whatever treatment the doctors suggest you have to try it:

> *...but if they [the doctors] said it's needed, you've got to try anything, haven't you? (Angela)*

Angela said that in some complicated situations ('big' decisions, as described by Sophie) that she saw while being in the hospital, the women were quite happy to take the surgeon's advice:

> *Well, I had seen cases that have been more difficult than my case was, that have been in [the hospital] more than twice. So obviously they had more to think about, but I think that in these cases that I can recall they were quite happy to take the surgeons advice. (Angela)*

Lynn also expressed a great deal of faith in the doctors and the hospital:

> *... but because I am so* ***confident*** *in [the specialised unit and the doctor], and feel perfectly that I am treated well, that I had no doubts*

at all that they are professionals, experienced and have expertise and everything... (Lynn)

Sophie said that such trust in the doctors develops because they are honest about diagnosis, and used the word 'cancer' straight away:

They said right away 'we think this is cancer' you know, so ***I trust them*** *now, so when he [the doctor] said that 'things are going well, things are good for the future' I believe that. I'd rather have that than somebody saying 'Oh, don't be silly, of course you will live to see your children grow, of course you will live to see your grand children' that is not what you need to hear when the results come back, you want to hear the truth, but in the right way. (Sophie)*

NC 1 thought that women generally were happy to leave the decisions on treatment to the doctors. She was asked about it, and this was her response:

IK: Did you hear often the type of saying "I prefer the doctor to make the decision, I don't want to make a decision, he's the one with the knowledge and the experience", is it something you've heard regularly?

NC 1: Oh yes. Very common. And it's a justified comment, particularly working in a team like this where they are really fair in their giving of information...

She was, therefore, convinced that such an attitude expressed by the women is justified. Furthermore she stated:

I mean the treatment is obviously the best type of treatment in this because it's been tried and tested through trials then it's fair enough that the doctor has had the experience, and it's not just one doctor making the decision, it's a multi-disciplinary team making the decision so I think these comments are fair. (NC 1)

NC 2 also thought that:

...a lot of them [the women] would rather the doctor said 'this is the treatment'. (NC 2)

NC 7 expressed the same understanding:

I think the majority of women though, would take the advice of the consultant. I think most women. The surgeon would say 'this is the treatment I think you should have or that you require', the majority of women will think the consultant knows best and go along with what he would recommend. (NC 7)

Another perspective was offered by NC 5, who thought that letting the doctor make the decision is also a choice:

...quite a lot of the women don't want the onus put onto them to decide. They feel that the doctors are the ones with the information, who know what's best and really they're the ones who should decide, but in a way they are still making a decision - they're saying 'well I want the doctor to decide', so in a way they are making a decision themselves... (NC 5)

In the group discussion with the 'Reach for Recovery' initiative, the idea that leaving the decisions on treatment to the doctor is a form of choice, was also emphasised by one of the women.

And at that point the only choice I was given was... and he [the doctor] said 'which do you prefer?' and I said that I had no idea, and all I could say was 'I leave it to you, whatever you suggest' which was giving me a choice, I chose to let him make the decision and not let me make the choice. And he said 'if it was my wife I would... and I said 'fine, I will go along with that'. But I did actually get a certain amount of choice... but having been given the choice - I can't get round on him and say 'right, I let you decide...'. (DG)

In summary, the great trust in the doctors expressed in this research can be explained by several factors. These factors, in my opinion, can be divided into socio-political, cultural, and institutional influences, as well as psychological motives.

The first influence is the socio-political one. British people in general, and Scottish in particular, still possess a more traditional view of medicine than, for example, the views held in North America. The philosophical basis for the provision of social and medical care in Scotland was based on the Church system, which gave equal access to all people. At the same time, it was also decided by which doctors everyone would be treated, by providing clinics that were responsible for specific areas or sections of the population. Consequently this has created a dependency system. In direct contrast, in North America health care is primarily provided by a market-oriented system. In the US, therefore, the patient is educated to be a buyer of medical information and advice. The term 'doctor shopping' is well suited to describe the situation there. In the UK, however, there is a more traditional view of the doctor as having a great deal of power and authority. These philosophical differences would lead one to conclude that the average North American woman would talk quite differently on these issues. She might be more sceptical, perhaps more assertive and would search for the 'best' advice. There may be more questioning regarding the doctor's expertise.

The second influence is the cultural one. Historically, the western world has been based on a patriarchal system. Scotland is not different in that respect. This has resulted in a male dominated culture, where women have very few rights, and thus are dependent on men in many aspects of life-decisions. This situation is replicated in the hierarchical structure of medicine, where consultants are predominantly male. It is, therefore, not surprising that some transference of this socialisation process entered as an influencing factor into the decision-making process regarding the treatment these women were faced with.

The nurse counsellors who were interviewed in this study mentioned the influence of culture on the women's attitude to decision-making. They all thought that the Scottish women in particular, took a somewhat fatalist and non assertive role when being faced with the options concerning treatment. They compared the behaviour of the Scottish women, who they encountered in their daily work, to what they heard about the American, or even the Southern English women's attitude.

When questioned about this issue, NC 2 said:

> *IK: Did you find also women that said 'but I have the right to make this decision, it's my body'?*
>
> *NC 2: No. I find that the people here in this area really don't seem to have that feeling. I don't know what it is but they don't react like that here. Whether it's [local] or Scottish people, but there seems to be a difference from what I heard about and read about...*

NC 5 seemed to have been in favour of the more 'easy going' attitude of the Scottish women she knew:

> *We have more problems with people coming from England, south, than we do from the local people. It's that they are so knowlegeable [the English] about everything, they question everything... I sometimes feel they question a little bit too much and get themselves worked up about it, because they know so much. There's in a lot of the local people the case of 'the doctor knows best', I come in, I do what he tells me and get on with it and get back to normal. (NC 5)*

NC 6 summed it up as:

> *...women are very much more with it now with the media, and they won't just be pushed into whatever the doctor thinks. But on the whole the North Eastern woman is inclined to accept what the doctor says, you know. They've got that kind of culture. (NC 6)*

The third influence relates to the institution. In this context, all the interviewed women were treated in a specific breast care unit that is acknowledged as one of the leading breast cancer clinics in the UK. Both the ethos and the medical practices within that unit appeared to be of great significance for the faith developed by the patients in their doctors. The unit aimed at making the experience of cancer one which for the woman is as lacking in stress as possible. The place has become a 'second home' for women undergoing treatment for breast cancer. The attitude and the sensitivity that the doctors practised was remarkably appreciated. As Lynn said: "They treat the person, not just the illness". The unit generally

provided a pleasant and reassuring environment and it is no wonder, therefore, that this view was expressed.

In relation to nursing, this topic has important implications. The nurses in the unit were reported also to have faith in the doctors and there was a good working team atmosphere. The nurses conveyed this trust in, and good relationship with, the doctors to the women. It is not the aim here to analyse the nurse-doctor-patient relationship, but I believe that it is an important issue for future examination. Nurses should be a part of the doctor-patient relationship and understand some elements of their role in that context. As one of the women at the 'Reach for Recovery' meeting said "I think the nurses are a very important bridge between the doctors and patients..." (DG). Bishop and Scudder (1990) said that: health care practice should primarily be understood as a human enterprise concerned with the caring relationship between physicians and nurses and ill persons.

It was Engeldhardt (as described by Bishop and Scudder, 1990) who first designated nurses as the 'people in-between' because nurses give their care under the scrutiny of two rather powerful individuals: the patient and the physician. The physician's power comes from his authority in health care matters which results both from his greater knowledge and technical skill in medicine and from the legal right to prescribe drugs and perform essential lifesaving and pain-reducing procedures. The patients have the right to decide what they will allow to be done to them. Thus, although patients are often disabled by disease or are ignorant concerning their condition and prognosis, they join as co-equals with physicians in authorising therapeutic endeavours. Thus, nurses are caught between doctors, on the one hand, who are authorities regarding scientific and technological knowledge, and **are in authority**, and patients on the other hand, who give authority for health care endeavours (Bishop and Scudder, 1990). In the case of breast cancer care, nurses can easily find themselves 'in-between' a doctor recommending a certain treatment, which the patient refuses or objects to.

Bishop and Scudder (1990) concluded by pointing out that:

> Those in health care should not base decisions on what they believe patients 'should want', it does not focus on protecting the individual's right to do what they want to do. Instead it affirms that patients ought to be assisted by nursing to authentically exercise their freedom of determination. (p.23)

The nurse's understanding of the woman's attitude towards her doctor is, therefore, important when dealing with the issue of decision-making as regard to treatment. It is a well balanced doctor-nurse-patient triangle, in its medical, socio-political, cultural and institutional context, that should ideally provide the woman with the optimal conditions for making the decision with the best quality information, advice, and support.

The Right of Choice

The ability to determine one's own identity and to make choices affecting one's own life is unique to mankind. The right of free choice is not only a political issue but with reservation also an important facet of medical ethics. In the modern democracy it is believed to be an element of fundamental human rights. Breast cancer care is an example where such a right can be practiced. As discussed earlier, the freedom to choose one's own treatment is a growing feature in the medical treatment of early, primary breast cancer.

The women interviewed in this work had an opportunity to practice this right. They were all involved in decisions regarding their treatment in one way or another. A major difference between the women was the extent to which they **actually** wanted to make these choices themselves, and how much they believed it was their right. This is closely connected to the previous topic which dealt with the attitude towards the doctor. Like the previous topic, it is also influenced by cultural education. In general, the women themselves did not raise the issue of the right to choose, but it was initiated by me. This by itself is an interesting fact, and shows perhaps that it is not a thing most of the women have automatically thought about. Ruth was an exception. She was the only woman who felt more willing and competent to make decisions. She was a well informed and knowledgeable woman. Her husband was a scientist working as a health physicist in the area of radiation protection who understood some of the

medical background to the treatment options Ruth had. This was important for Ruth because she could consult another knowledgeable person. She thought that the doctors should give advice and discuss things with the patient, but ultimately it was the patient's right to make the decision:

> *I think that, I mean it's you,* ***it's your right*** *and if you feel that way and you manage to get over it, then I think it should at this stage at least be reasonably discussed, em... I think a lot of medical people still don't either discuss or tell you enough em... about... well after all it's you, you know, if it was you sitting there making decisions for me em... O.K you have got the knowledge about me to recommend and to say 'this would be best for you' but I still think the decisions should be mine. Em... and then you should have talked me out about this decision. (Ruth)*

Angela thought that nowadays there are simply more options because of the development in the medical care, and she therefore was in favour of the patient being involved in making choices:

> *Of course nowadays there are more options then there was say twenty years ago, but oh yes, I think the more the person is involved - the better. I think it's a good thing that you are involved and every option is explained to you and you can weigh it up and decide what you want or what you prefer. (Angela)*

Susan looked at it as an ethical issue and said:

> *...so I think ethically that it's good they had you have a choice. (Susan)*

Some of the nurse counsellors also thought that nowadays women are more demanding of the right to take part in the decision-making regarding their treatment. As NC 6 recounted:

> *I would say when we started 8 years ago they didn't demand much of a decision, they didn't... But because of the screening that started and lots of things on telly and in the papers, the women are really*

becoming more responsible for themselves and they're coming with a totally different view of how they want to be treated...

...so I think the climate is changing very very quickly round doing the decision-making. (NC 6)

Nurses should prompt women to exercise the right of choice that they possess, by the very nature of being patients. It seems that the women in this research were in some respect ignorant concerning this right. This was particularly exemplified by their attitude towards the participation in clinical experiments, having a bad conscience if they refused. It is something we have to teach women, in order to make sure they are not deprived of this basic right. However, we also have to acknowledge the danger of patients choosing against their recommended treatment, or even refusing treatment altogether. Conversely, some women opt not to exercise such a right, and it is important to respect their choice of leaving the decisions to someone else.

Wanting to be Helpful

As a continuation of the issue of the relationship with the doctors, the women talked about the fact that they wanted to be helpful as patients. It was a sincere expression of gratitude to the people whom they thought had helped them. This idea was raised especially with regard to participation in medical trials. The women usually agreed to take part in clinical experiments, and the main reason they gave for that was that they wanted to be helpful, if possible. It was interesting to note that none of the women mentioned the fact that it might help other patients in the future, or that it is a contribution to science and to the understanding of breast cancer and its treatment. They saw it very much as related to their relationship with the doctor. The wish to be helpful, therefore, affected in many cases their actual decision-making about treatment .

Lynn had a choice to enter a trial for her adjuvant treatment. She had no doubt that she would join the trial, in order to be helpful. The trial meant that she would be randomly allocated to chemotherapy, radiotherapy or ovarectomy. She was allocated to chemotherapy:

In my case I wanted to be as helpful as possible and therefore the study seemed the right thing.

I think I just generally wanted to be helpful... you want to help the people that are helping you. (Lynn)

Sandra also said she would be happy to help in a study:

...they told me about the study, and if I can help in a medical study I am willing to. (Sandra)

Rose had a slightly different story. This was how she remembered it:

And on the Wednesday I went back to [the specialised unit] and they told me to come in for an operation on the following Wednesday, a simple lumpectomy with taking out a few lymph glands. I had the operation on the sixth of June, but had all the lymph nodes taken out, because [the doctor] is doing a study on how it will affect people in the years to come whether taking all the lymph glands out affected or not at all. (Rose)

She thus was experimented on, without her knowledge or consent. At a later stage she was then asked whether she would join a trial for the adjuvant treatment. As mentioned earlier, Rose rejected the offer, fearing she might be allocated to a treatment that would have an adverse effect on her coping ability, but felt rather guilty about it. A discussion she had with the counsellor, and later with the doctor, reassured her that she should do as she felt, and that they could manage without her. She felt even less guilty when realising that she was actually a part of a previous medical trial in relation to the lymph nodes:

And I felt dreadful at letting people down [by not joining the trial], you know, I thought it wasn't right and then [the counsellor] said it didn't matter at all, it was my decision and it wouldn't make any difference, and the doctor said that it didn't make any difference, it was my decision, and as I had all the lymph glands out for the trial, I didn't feel as guilty. (Rose)

NC 7, based on her experience of working with women with breast cancer, also understood that for many women the motive for choosing to enter a trial is the wish to be helpful. In a rather cynical tone she said:

> *...the majority of them [the women] say they will agree to the trials. It's explained to them what the trial is on... I suppose they think they're helping. They would think they were helping the doctors, so eh... I don't think any of them really considers it too much. (NC 7)*

It seems, therefore, that it was some sense of obligation that made the women join the trials; they felt the need to 'be helpful'. However, both Lynn and Rose said that there was no pressure on them to enter these medical trials and that it was up to them to freely decide whether they wanted to take part in such a trial or not. It is extremely important, in my opinion, that nurses ensure that patients join medical trials, as well as nursing and other para-medical research, from their own choice. Any pressure on the patient to take part in a medical clinical study, even out of a sense of obligation based on gratitude, gives that study an unethical character. This is why I have aimed in my study to interview only women who approached me of their own free will. Although it allows bias to enter into the results, this should be the situation in any form of research involving human beings, especially those needing medical care. Nurses have great responsibility to ensure that this is the case with their patients, a fact that many of them indeed appear to be aware of.

Rabbi Julia Neuberger performed research in the area of medical ethics. She studied in detail, over a year, the performance of 28 regional medical research ethics committees around the UK. Most committees had just one nurse member; 12 per cent had none at all, and seven per cent had two or more nurses. One of her most interesting observations was that those committees that had nurses as members had higher rejection rates of research protocols (Neuberger, 1992). These findings suggest that nurses tend to take ethical issues into account when doing their own research, or when helping medical and para-medical professionals to carry out their studies.

The Importance of Support

The Self-World of the women, which, in the context of breast cancer confronted a new reality in the realtionship with the doctor, sought a new dimension of expression. Another way to understand this, is that the altered Self-World needed to regain its place within a social context. That is where the social network of support played a major role. This network consisted of the husband or partner, the whole family, the close intimate relationships, and the broader group of friends. An additional most important part of the network of support, as described by the women and the nurses, was the peer-group of women who had also experienced the disease. All these sources of support are further discussed in the following section. Support, therefore, may be seen as enabling the women to come back to their social world of self. In the context of the illness and decision-making, support in most cases helped the women to go about this most stressful and demanding situation.

The Role of the Husband/Partner

All but two of the husbands of the women had an important role and were involved in the decision-making undertaken by their wives regarding their breast cancer treatment. Two issues were discussed in this aspect: namely, the effect of the illness and the decisions about treatment on the husband, and, the support given by the husband to his wife in the decision-making situation. These two issues were closely connected. Two of the women were single (Susan and Angela) and one divorced (Lynn). Both Susan and Lynn, however, talked about the support they received from their current partners. Angela, on the other hand, did not refer to any significant male figure during our conversation.

Jill described how her husband reacted. He had suffered a heart attack about a year before Jill's diagnosis, but when the breast cancer was diagnosed he immediately adopted a supportive role and tried to be as helpful as possible:

> *...when they [the doctors] said 'go for this and do that' he [my husband] thought about me and right away he was behind me taking me to the surgery, rushing with me to the Royal... he was in*

the [specialised unit] with me at the time of the final decision-making. (Jill)

Initially Jill was told that lumpectomy would be sufficient, and only at a later stage was it decided that mastectomy was required. This was a shock for her husband who had not expected this. As Jill said:

..on the Wednesday, and he [my husband] was there with me. Well, I mean, when we knew it all on the Tuesday he [the husband] said 'that's fine if they need to remove the lump and give the radiotherapy...' and then on the Wednesday when I told him that there is going to be a change of plans he was a bit shocked, you know, but he said 'if you can handle it then you go for it', he quite admired the way I handled it... (Jill)

Mandy and her husband were very close, they did most things together, including their hobby of playing Bridge. While Mandy was recovering from the mastectomy operation, her retired husband was able to help her at home.

Fortunately my husband is retired, I didn't retire yet, so he is in the house all day with me and really didn't give me anything to do. If I lifted a teaspoon he would say 'put that down', so I had a lot of good care and attention from him after the operation... (Mandy)

Mandy decided to have the mastectomy, because of the risk to her heart from the radiotherapy. She said in the interview that her husband was also in favour of her having the mastectomy, but for a different reason. He thought that if she had the breast removed the cancer would be gone. It was a great support to get this reassurance from her husband:

...when I told my husband, I said '[Phillip], it's going to be a mastectomy', do you know what my husband said to me? He said 'I'm glad you have decided to have a mastectomy, because I wasn't happy with the thought of you having five weeks of radiotherapy, because to me they will not be sure you had the cancer away, if they take your breast off then your cancer is away'. (Mandy)

Ruth's husband was supportive in a different way. He was a physicist by profession and worked in the area of radiation protection. Ruth had a lumpectomy done and was later given the choice of whether to join a trial for the radiotherapy treatment or not. If she did not join the trial she would have automatically had the radiotherapy treatment. However, if she joined the trial she would be randomly allocated to either have the radiotherapy or not. Two reasons made Ruth join the trial, and these were related to her husband's advice since he had the academic knowledge. One reason was that being a scientist, he was in favour of trials which are a part of medical research. The other was that he had knowledge of radiation. This made Ruth less frightened of the treatment, unlike many other women who were perhaps inadequately informed about it.

> *...as soon as I suggested it to my husband [that I joined the trial] he thought that any sort of trial is a good idea, I mean the more stuff that is recorded, not just about breast cancer, but you know, the more research is done the better. So he was quite pro and so I was...*
> *... again, as I said to you, I had some knowledge, you know, how short it would be, the period of actual exposure each day [to radiation] and all the rest because my husband is in the business so to speak... (Ruth)*

Lucy's husband was also with her all through the breast cancer experience and when she had to make decisions. He accompanied her to see the counsellor and found it important to be involved and to know what was happening to his wife.

> *My husband was really fine, he says to the counsellor 'I really enjoyed coming along here' he says, and she was listening and he said 'it was good to know exactly what is happening to my wife, because years ago there was never this'. She says 'Oh I know' she says, 'it's nice that you came along to everything'. (Lucy)*

Lucy and her husband had a friend who had had breast cancer, diagnosed a few years previously. This has come as a shock to their friend's husband who received little support himself and therefore could also not be supportive to his wife. It was an extremely traumatic experience for that couple, as Lucy described it. When Lucy and her husband met their friends they tried to encourage Lucy and her husband and to tell them how

important it was that Lucy's husband was involved all along and that he had people in the hospital whom he could talk with.

> *...and she says [the friend to Lucy] 'so what you have got is just great' and she said to my husband 'you have gone along with [Lucy] and they told you exactly what is happening and they asked you how you felt about it and everything...' (Lucy)*

For Susan and Lynn it was their current partners who gave them emotional support. Lynn, who was divorced, met her partner a short while before she was diagnosed as having breast cancer, and it was therefore still a fresh relationship. Lynn talked about the difficulty that her new partner faced having to cope with her illness.

> *As it happened I just met a friend, a male, in March before this happened. Somebody I knew from twenty years ago, he got a promotion and moved away... and we have just remet and we have just built up the relationship. So he was thrown into the trauma of coping with his girlfriend, as it were, who had such a personal thing... (Lynn)*

Both Sandra and Sophie said that they did not get much support from their husbands. Sandra described her husband as very quiet and said that she wished there would be someone to talk to. Her husband was not the right person for that. Sophie also said that she could not really talk things over with her husband since she thought that he could not cope with it. It was a protective attitude she has adopted.

> *I had a stage when I held a lot back from telling my husband because I don't think he copes as well as I do; I tell him about the good things but I don't tell him what's in the back of my mind - that I am worried about the future and all that, I don't tell him that. (Sophie)*

Sandra and Sophie's husbands could therefore not help their wives to make decisions regarding treatment, they could not give much support at that point. This is where the two women described themselves as being in the need of counselling - of someone to talk to.

At the 'Reach for Recovery' meeting the women discussed a related topic - the husbands' need for support. They realised that their husbands were often not involved enough in everything which was concerned with their illness and the decisions regarding treatment. This in turn, they argued, influenced the husbands' coping with the situation and their ability to support their wives. The women suggested that their men should get together and learn to draw support from each other. The head of the 'Reach for Recovery' group said that there was an attempt to form such a support group in another Scottish area, which worked rather well:

> *- I would say... I think the husband should be brought in and become a part of it and be considered actually, but as time goes on you [the woman] begin to meet more and more people and the husbands are the ones that don't meet them. They don't have anyone else, they are talking about forming a group, I think the husband... men are not good at getting together.*
>
> *- But has anyone ever done really anything yet to make them... ?*
>
> *The head of that group - Yes. About four years ago I helped getting started a group in Fife and they met, again once a month, like ourselves, and quite a number of the husbands came... (DG)*

It is difficult to make an overall statement about the role of the husband or partner in the decision-making process. It is obviously a function of the type of relationship the couple has. It seems, however, that husbands who received some form of support themselves were more able to be supportive to their wives in that difficult situation. Husband-directed support can have many forms: support groups for husbands, involvement in counselling sessions and support from the wife herself. Interestingly, mixed husband/wife support groups were not suggested. It is well known that for any family member, especially for the spouse, the reality of cancer can be even more stressful than for the patient herself. It is not unusual to see a cancer patient comforting her partner and family and giving them reassurance, rather than the other way round, as we would expect. The husbands of breast cancer patients who face a decisional crisis with regard to their treatment are in a particularly sensitive position. On the one hand they often are the people to whom the woman feels closest and whom she most commonly approaches for advice. On the other hand, they usually

do not have the knowledge required to give such advice and therefore feel incompetent. According to the women, most of the husbands also felt that it was not their right to make any decision on behalf of their wives but that she should make her own choice alone, as most suitable for her, without their influence.

The Role of the Family/Children

The role and place of the whole family, particularly that of the children, in the decision-making process was also addressed by the women.

Rose said that her husband was supportive. However, she talked more about the whole family unit rather than specifically about her husband in relation to support at decision-making.

> *...but I am lucky I have a supportive husband and a supportive family...*
>
> *IK: Who did you involve in deciding to go for radiotherapy?*
>
> *R: My family. My family agreed, they didn't want me to have chemotherapy. If I would have said 'yes, I want chemotherapy' they would have said 'yes, fair enough', but they didn't want me to... they didn't know enough about it [the chemotherapy] either. (Rose)*

Sophie had two young daughters and felt a responsibility towards them. She felt in the centre - being protective towards her husband and her daughters. She gave this as the reason for her decision to fight the cancer:

> *I look at them and I say 'I have got to be there for them [my family], I have got to see them [my children] grow up and me being there, I can't go - I have not finished to do what I am meant doing with them.*
>
> *I think on the whole I cope quite well... you have to I think, if I didn't have the children maybe, you would certainly... but when you've got them you've got... they need you, nobody else can do what I can do, so I have got to fight it... (Sophie)*

Rose also very much felt a sense of responsibility for her family's life. This and her role in controlling the family's life affected her choice not to have the chemotherapy.

Lynn was a single parent, divorced nine years before. She had raised her thirteen year old son alone and inevitably felt a great responsibility for him. Her illness made this even more acute since she had to cope with a threatening situation, while at the same time protecting her son. She called her son 'my dependent':

> *... I have nothing against single parents, but if you have a child on your own, and I have for 9 years now, you have this person as your responsibility, and therefore my thoughts were what will happen to [Richard], and not so much of myself. I really wasn't thinking about what is mastectomy, what lumpectomy was, it was really* ***my dependent*** *and what will be with him. He doesn't see his father at all, and by whom will he be looked after? That was awful - the thought of what's going to happen to my son. That was really the worst thing. (Lynn)*

The wedding of Ruth's daughter was pending when she received her diagnosis and was informed about the treatment. The wedding was to be held in London and Ruth said that when she was told that she had breast cancer the only thing that was on her mind was whether she would be able to make it to the wedding. This was the main reason why Ruth was happy to have the lumpectomy, since it meant a short treatment period and she would quickly return to her function as a wife and a mother.

> *I am happy that they did say that I could get to my daughter's wedding... so it was really quite honestly the only thing that was on my mind, 'cause what I asked was 'when?' and 'can I go?' and it was the first thing that she [my daughter] asked about too. You know, we really had, strangely enough, a big family gathering... it was going to be one of our best get-togethers and I wouldn't have wanted to miss it. So I must say that that was more in my mind, that I will manage to get down there, than anything else, you know. (Ruth)*

The role that these women felt as wives and mothers had a strong connection with their coping with the disease and the decisions involved.

It was a distinctly feminine and motherly identity that led the women in their decisions. It is important that nurse counsellors understand these influencing factors as playing a major part in the woman's decision-making.

Social Support

The importance of social support in the decision-making process was also examined and so I have distinguished it from family support. Social support was related to one particular relationship, to only a few (as in Angela's case) or to a larger group of people (as described by Mandy).

Angela was not married and had no close family. She had one school-friend to whom she was very close and who was her main support during the breast cancer experience. That friend was a widow with no children. Apart from her Angela had a few other friends, such as Susan, whom she met at the hospital. Angela said that she was happy and satisfied with these relationships and did not feel the need of more social support or more people around her.

> *Well, as I say, I have got a very good friend - I haven't got any close relations, I was an only child, my parents are dead, a lot of my cousins are dead, some live abroad, some... you know, em... but I have got a very good friend from school days, that's the one I go with on holidays - she is a widow now, her husband died a few years back and she has not got any family. So when I went out of hospital I went to stay with her for two to three weeks until... no, I stayed with her for a fortnight and she came up to my house and stayed with me for a week until I got better... but I didn't feel the need for any outside support, no. (Angela)*

In relation to the decision-making that Angela faced, she did not need any support from more friends. Her contact with Susan was sufficient and enabled her to discuss things concerning the illness, its treatment, and the decisions involved. Even though she had no close family for support, Angela presented herself as an independent woman with little need for help from others. Social support was for her related to a very small circle of close people who became for her like a family.

For Mandy social support meant a slightly different thing. She and her husband belonged to a Bridge Club. This provided a large social group. Mandy said that she received a lot of support from the people there. This was important for her coping with the illness, treatment and decisions involved.

> *My husband and I go to the Bridge Meeting Club, my husband is the chairman of this club, and before the operation and after it they phoned me up and asked how I was. And when I went to hospital to have the operation the amount of cards that I received, the bunches of flowers that I got...*
>
> *... and the first day I went back to the club with my husband they announced 'Let's welcome Mrs. M who is back after having a serious operation' and that was a big moral lifting as well, to know that people care, that is important. (Mandy)*

Mandy saw the illness as having a positive side in connection with her social support. It was through her illness that she and her husband realised how many friends they actually had:

> *You don't realise just how many friends you have got until something like this comes. We have found that we've got Oh Gosh, dozens and dozens and dozens of friends... (Mandy)*

These examples show what different forms social support can take, and consequently, how differently it may affect the decision-making process. In Scotland, in general, people tend to stay close to their family environment and it is therefore logical that this is where their support comes from. External social relations play a lesser role in the support system, as described in this study. This is, however, increasingly changing, so that in the future differences might become more noticeable.

Women to Women Support - the Breast Cancer Unit and Self-Help Groups

The sense of togetherness shared by women with breast cancer and its implications for their coping ability was a major theme arising from the interviews and the discussion group. Women talked about this feeling of

togetherness in two main connections. One connection was the specialised breast cancer unit where they were all treated. This was a hospital unit only for breast cancer and therefore all the patients suffered from that same disease. Being together with women who also had breast cancer was of great benefit. It provided a special opportunity to share experiences and emotions related to the disease and to enhance the feeling that they are not isolated. The other connection related to self-help groups. These were formed by women who had breast cancer and believed in sharing, talking, and supporting each other.

A description given by Jill of the interaction between the women in the ward is typical of the examples given by other women:

> *We all introduced ourselves and had a chat and each told what she was having done, we all wanted to know how each got on at the staging. Everyone was different, we were different people - different women, but we all listened to one another. (Jill)*

Rose also described how important it was to be together with other women who had breast cancer. Through them, she felt, she could learn how to cope better with the situation. It was also a way to gain more knowledge about the disease. The common experience is an ongoing one:

> *Since I have known I have got breast cancer, lots of people come to me and say 'I had a lumpectomy...' or 'I had a mastectomy...', before that nobody said, but people do now. But then I didn't know enough about it, I needed to be with people who have had the same thing as me... (Rose)*

Lucy had two friends who had had breast cancer in the past, and she found them of great support.

> *So there is two of my friends [that had breast cancer] and they are fine, and they look at me and they say 'you just wanted to join us...' and I just laughed... but they kept me going... (Sophie)*

The idea of a breast cancer unit that brings these women so closely together was questioned in the discussion group. The view was expressed by the participants in the discussion that perhaps for some women this is too much - to be all the time with other women who were suffering breast cancer.

> *- I have a friend that very recently had a mastectomy at [the specialised unit], and she found this sort of togetherness and the thing of breast cancer too much, and she used to go and lock herself in the bathroom, she didn't want everybody else to know...*
>
> *- Yes, you sit in company with other patients with breast cancer and you are talking about it, and you have all different problems but you could think 'Oh well, I am going to get this as well...' (DG)*

Angela expressed a similar view but in relation to the self-help groups. She did not feel the need to join one of these groups, and thought that it would only involve discussion about breast cancer which she tried to avoid in order to get on with her life.

> *I just don't feel any need for that [joining the meetings of the 'Reach for Recovery' group], and there again I think it would be nothing but cancer cancer or breast cancer breast cancer, you know. (Angela)*

The topic of peer group support was related by the women to that of counselling, which will be more fully discussed in the next chapter. They said that counselling as a support system has its limitations because if one has not **been there** then one cannot truly understand the woman faced with breast cancer and the decisions about treatment which need to be made. It should therefore be stressed that the idea of **having been there** is an extremely important aspect which enables women to support one another in the experience of breast cancer. When looking for advice and understanding in a situation of decision-making, it is other women that **have been there** who can offer help and support. Susan summarised it by saying:

So if you've been through it you can then try and give them a fair advice, because you know what these people are going through because ***you have been in that path before...*** *(Susan)*

She continued by telling:

...we all meet [the women that were hospitalised together with me at the same time], and we find that we now, if we meet together and discuss things we actually find that more comforting than having to look for a counsellor, you know... (Susan)

Lucy shared Susan's views. She also thought that the talks between the women were extremely important and that **having been there** is a prerequisite for good support, since they know exactly what the other feels.

I mean there have been people that really have been upset. There was a woman the last time I was in who was very upset and I said to her 'come on, sit beside me, is it your first time here?' Certainly you know how she feels because you ***have been through it****, so you know exactly how somebody else is feeling... (Sophie)*

Lucy felt strongly that if you **have been there** you must know exactly what the other woman, faced with a similar situation, is feeling. She did not question the idea that women are different and that their reactions to the situation may vary and therefore one may never know what the other woman exactly feels.

There seemed to be something unique that these women felt they could share. This related to feelings of feminine identity and attitudes described earlier on in this chapter. The majority of nurses are women and as such they could probably well understand and appreciate the uniqueness of what these women share. It is important that as nurses we see the special feminine aspects that we share with women faced with such decisions, but that on the other hand we realise our distance from really understanding these women by the very fact that we have **not been there**. This distance may have positive, as well as negative connotations.

Summary

In this chapter an account was given of the major topics the women and the nurse counsellors discussed in relation to the decision-making process. Twelve themes emerged when analysing the data.

The women's Self-World was the reality firstly described. Here a description was given of the themes that demonstrated the personal inner world of experiences in relation to the confrontation with the diagnosis of breast cancer and the decision-making about treatment. A distinction was made between being alone and feeling lonely. The women talked about feeling alone during the decision-making experience even when supported by relatives and friends. They also felt lonely at times, but this varied according to the support they received. The views of the women and the nurse counsellors also demonstrated the difficulty associated with the decision-making situation. This was further discussed under the next theme of 'the burden of making a choice'. Age and personality type, and the general outlook on life, was another theme described as influencing the decisions about treatment. Further, the concept of health was looked at. A positive outlook concerning their own general health, had a positive effect on the ability of the women to cope with the situation. Only one woman conceived of herself as potentially seriously ill. This promped her to take adjuvant therapy while avoiding discomforting treatment.

The personal feeling about the breast was an extremely sensitive topic. The women talked about two major themes. One theme was related to the breast as a symbol of femininity and connected to body image and sexuality. This issue played a minor overt role in their decisions concerning mastectomy and breast reconstruction. In a more covert way, it may be of greater significance in the choice of treatment. The other theme was related to the breast as a hostile organ since it contained the disease. The general view expressed by the women was that they 'just want it away'. The women commonly said that feeling confident that the cancer was away, which was achieved by having the mastectomy, was more important than preserving the breast. However, they did not mention the possibility of later metastases.

The relationship with the doctor represented a different social reality. There was an interaction which came from outside the Self-World. The doctor was the first social encounter the women had, with regard to their breast cancer. The women expressed complete trust in the doctors and strongly believed that the 'doctor knows best'. This clearly influenced their decision-making about treatment. Even when offered a choice of alternative, equally effective treatment procedures, the women generally chose to leave these decisions in the professionals' hands. A general sense of gratitude to the medical staff was a common feeling, and the women said that they wanted to be helpful to the ones who helped them. This expressed feeling motivated most of these women in deciding to join medical trials. The idea of the patient's right of choice in the health care situation was then examined and some ethical implications and considerations in that context were discussed.

The available network of support was perceived as extremely important throughout the initial time of diagnosis and the decision-making about treatment. Support was a social process by which the women could come back to a reality of a Self-World. The power and control that the women had, which they chose to give the doctor, was regained through the help of the network of support. This happened in two ways: support that was clearly directed to the women, for example by their husbands or by other women that had breast cancer, or support that was gained indirectly, by caring for the children. In the latter case, support was combined with a great sense of commitment and responsibility.

The support given by husband or partner was very helpful to those who had it. Those who were not supported by a partner learned, however, to not require it. It was generally said that husbands needed at least as much support as their wives in order to cope with the situation. It was suggested that nurse counsellors and self-help-groups for husbands could facilitate the ability of husbands to cope and support their wives.

Being supported by the family was not of prime importance. Rather, the patients conceived of their family as dependent on them. The necessity to care for the family, mainly the children, stimulated them to fight the disease and at least in one case it decided the course of therapy. The larger

circle of friends played a variable role. Some women were comforted by the support of numerous friends. Others prefered only one or a limited number of very close friends. The last theme - peer group support - was a special one for the interviewed women, since they were all treated in a specialised breast cancer unit where all the patients had breast cancer, and therefore shared a similar experience. Additionally, some of the women found their support by joining self-help-groups organised for women that suffered from breast cancer.

Chapter VIII:

THE ROLE OF THE NURSE COUNSELLOR

Introduction

Nurse counselling was a major topic in the discussions with the ten women who were interviewed, and the nurse counsellors themselves. The meaning that counselling had for these women, especially at the time of decision-making, and its relation to nursing, were the areas that were discussed. All the women received counselling from the specialist breast care nurse counsellor at some point during their illness. Furthermore, the understanding that nurses employed as counsellors had of their role was also explored.

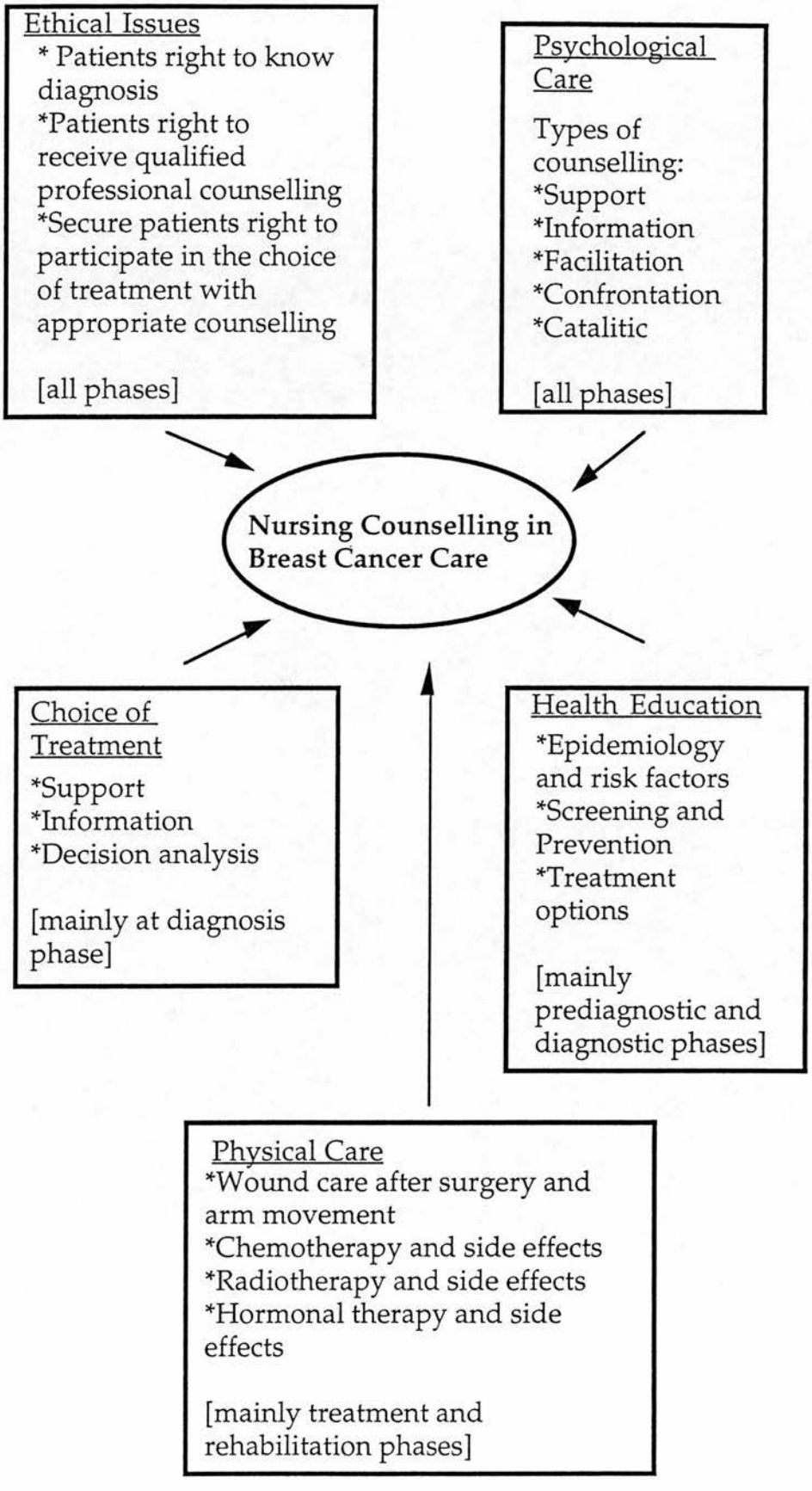
Six major themes emerged when analysing the data in relation to counselling. The first was concerned with the **timing** of counselling. The two major points at which counselling was found most needed were at the initial hearing of the diagnosis, and at the time the final decision regarding treatment was made. The second theme was counselling as a source of **explanation, information, and advice** in the decision-making process. The third theme related to the **emotional support** given by the specialist breast care nurse counsellor during the breast cancer experience. The forth was the idea of nursing and the **holistic approach**. The **education and training** of the counsellor comprised the fifth theme, and the sixth theme addressed the **limitations** of specialist nursing counselling. These issues are discussed in turn.

Nurse Counselling as Seen by the Respondents in the Study

General Comments

Nurse counselling in breast cancer care in general was related to five topics associated with the illness. These topics included counselling in the area of health education, physical care, psychological care, choice of treatment, and finally, ethical issues associated with counselling in breast cancer care. Each of the aspects of counselling was found predominant at different stages of the illness and treatment. The general areas of counselling in breast cancer care were partly discussed in Chapter 4, and are summarised in Figure 5.

Figure 5: Areas of Nurse Counselling in Breast Cancer Care



The respondents in the study expressed different views and gave their own definition of nurse counselling. Here are a few examples of how the women experienced the counselling they received:

> *Well counselling, I just saw [the counsellor] twice and I thought she was superb, I really did. Em...* ***she explained everything so clearly*** *to you, so that you understood what she was talking about.* ***She didn't use big medical words - she spoke in plain English*** *and I knew what she was talking about. She was a cheery person, and* ***she knew how to cheer you up*** *and lift you up. To me she is just an excellent person. (Mandy)*
>
> *I think it [counselling]* ***helps you to understand just exactly what you are going through, and how you feel...*** *It's more needed for people that maybe just cannot accept it, and there are a lot of people that cannot accept it... (Lucy)*
>
> ***It [counselling] is explaining things*** *that you don't necessarily ask the doctor, you may forget to ask the doctor, or feel his time is too limited. He is trying to fit too many people to too short a time, so simple questions could be answered better by a nurse. And so, feeling more at ease with the nurse - crying and all that sort of thing.* ***I could cry in front of the counsellor,*** *I never cried in front of the surgeon - I always wanted to appear brave in front of him, and I cried every time I saw the counsellor, and that was good to be able to cry. (Rose)*
>
> *[Counselling is] ...making a friend.* ***Making a friend with someone who is on the medical team,*** *someone who knows your family. She [the counsellor] knows a bit about my family, the circumstances at home, you as a person... and doesn't really make your mind up, but* ***allows you to talk and cry or laugh,*** *at times. She becomes a friend, she* ***gets to know everyone...*** *(Rose)*
>
> *And the counsellor took me along to her room and she turned me around. She is the one person that was able to very slowly put me back in shape,* ***She gave me so much time*** *and I think that* ***this was when the news were really broken,*** *and she gave me* ***the possibility to go through absolutely everything...*** *(Lynn)*

Lucy summarised the idea of counselling in three major concepts. She said that counselling helps one to accept, provides explanations and enables to speak.

If people cannot ***accept*** *it then I think they need somebody to* ***speak to*** *that can* ***explain*** *if you've got any worries. (Lucy)*

The nurse counsellors also gave their general views of their understanding of their role:

So I see the role of the counsellor as an ***information giver, a patient's advocate, a monitor of her progress.*** *This is in an ideal world where you have time to see the patient through. (NC 1)*

So for somebody to spend time to ***cope with that patient's emotions,*** *that woman's emotions through this stressful time is quite essential because nobody else is doing it. (NC 2)*

I would see my role more as ***caring, supporting information-giving, enabling,*** *I mean there're a lot of things in that ... (NC 3)*

It's therapeutic. You're not just giving information and getting information back and exchanging, you're actually hopefully ***helping the patients to adjust*** *and I do feel the way I deal with patients does* ***help to relieve anxiety,*** *to make them better able to deal with the disease. (NC 4)*

I see my job as ***providing the women with knowledge*** *that they need to deal with their illness and* ***to be there to listen*** *so that they can voice whatever their fears are and also to be there to speak for the patient to the consultant... You sort of go* ***between the patient and the surgeon*** *so that they fully understand what is going on. (NC 5)*

I think our role is to try and ***ease them into a healthy attitude*** *towards the cancer and to deal with it. (NC 6)*

They [the women] think it's great, you know, that they can ***talk to you about problems*** *etc... that there is* ***somebody there*** *that is available to speak to. (NC 7)*

The Timing of Counselling

The respondents commonly expressed the view that counselling was most needed at two junctions in the breast cancer experience. The first is on initially hearing the diagnosis, and the second at the point of making decisions about treatment.

The initial hearing of the diagnosis was seen by all as a crucial point when close help in the form of professional counselling is needed.

Ruth looked at the whole topic of counselling in a professional way. She had worked as a Samaritan for a few years and therefore was involved in a certain form of counselling. She believed that counselling should be offered as soon as possible after the diagnosis is given:

> *I think perhaps you could always do with it [counselling] sooner, em... you know, by the time when you actually get through to the counsellor or whoever happens to be there if she is off, things are almost settled. In some ways you could do with perhaps seeing her at the time you are literally being told initially... you know what I mean at the screening place for instance. Em... I think you've got to be... On that first day when they tell you, you know, I think that's when most people would need it. (Ruth)*

Sophie remembered the first hours after she was told about her breast cancer. It was a nightmare, she said. In her opinion, too, it was important to have a counsellor to talk to at that early stage:

> *Obviously it is [counselling] more important at that stage because it is a nightmare those first couple of hours at the hospital, it's so new, it's so frightening, the more often you go the more homely it becomes, you start to build the confidence up in the staff. So she [the counsellor] is needed at the very beginning... (Sophie)*

Sandra said, in an open and direct manner:

> *I was a bit shocked at first, when I heard the news, I mean... it is really difficult and I was particularly in need of counselling then....*

I was a bit shocked when I was told... it felt rather... I was shaking really, and there wasn't somebody waiting for me when I came out [of the doctor] either. The person, the friend that came with me she had to go, so... but I phoned my husband and asked him to come and collect me, because it was just close to his finishing time, and I told him on the way home in the car. But he is very quiet - he doesn't say very much. So this was the times when I could have done with somebody to talk it over with, a counsellor. (Sandra)

For Lynn hearing the diagnosis initially was also a traumatic experience. She was told that she had cancer by a house doctor who was, according to her understanding, unqualified to deal with breaking the news. The doctor left her alone in the room when she was in a state of shock, panicking and looking for some help. Only at a later stage the consultant and the nurse counsellor came in. Lynn remembered this time vividly:

Everyone was trying to calm me down and get me back into proportion. And the counsellor took me along to her room and she turned me around. She is the one person that was able to very slowly put me back to shape, She gave me so much time and I think that this was when the news were really broken, and she gave me the possibility to go through absolutely everything. She asked me who would I like to phone. I was divorced so I didn't have a husband to phone, my mother is 77 and a widow, you can't call her to come and help me, so she was very good and she called somebody at my work because I had to go to my work during that day since I expected everything to be normal. (Lynn)

Susan remembered that everyone that was in the hospital, at the initial point of the staging and hearing the diagnosis and treatment options, was counselled by the specialist breast care nurse counsellor:

Em... that day, the day that I was told 'yes, it's cancer and a mastectomy is needed' I was counselled by [the nurse counsellor], everybody was counselled by her that had been in for staging, and she was marvellous but you're terribly confused, they've told you so much that it's really going in one ear and coming out the other. (Susan)

At that stage, said Susan, one is not really able to 'take anything in' and that is why talking to the counsellor and going again through everything the surgeon said is extremely beneficial.

At the 'Reach for Recovery' meeting a similar view was expressed by one of the participants:

> *All I can remember was that all was at the top of my head. I think some of the other women will agree, you just don't take it in at that time. You need somebody after that... you're not believing really. I feel that after that you need somebody - some counselling, somebody like [the counsellor] eventually. But I don't think everybody has got a counsellor - you know, not every place has a counsellor who really brought you down to earth and led you through it step by step. (DG)*

One of the nurse counsellors discussed in particular her understanding of her role at the time of initial diagnosis:

> *The nurse counsellor will say 'what did the doctor tell you?' and she will try to illicit that the patient understands that she* ***has*** *cancer. If the patient is obviously blocking that she's got cancer, the word, the nurse counsellor doesn't usually go over these barriers then...*
>
> *The nurse counsellor will try to see what the patient's perspective of cancer is, although often she's very much in a shock at that stage. (NC 1)*

However, said NC 1:

> *...we won't necessarily be loading emotional support at that stage. We will note that the patient is very tearful, and in fact we will be* ***relieved*** *if she is very tearful because if she's very tearful at that stage she's usually acknowledging the fact that she's got cancer and she will start moving through the grief process naturally herself. (NC 1)*

This is how NC 7 described her role at the time of initial diagnosis:

The consultant goes away, we can talk things through, I think that's vital for the patient really to cope with. They start, I think they start to cope then once the initial reaction's worn off and somebody is talking things through with them... (NC 7)

The other time when counselling was found valuable was at the points of decision-making regarding treatment. The counsellor was very important as someone with whom things could be discussed.

After having the mastectomy operation, Jill had the choice of treatment for her systemic therapy. The doctors gave her the option of having chemotherapy or undergoing ovarectomy. After hearing the treatment options from the doctor Jill became somewhat confused, although she knew that chemotherapy considerably frightened her. She was therefore more willing to have the ovarectomy operation. The counsellor was there to reassure her.

I came back to the clinic on a Wednesday for a check-up and as I said I got these other options [for the systemic treatment] which I wasn't ready for... I was still getting over the first operation. It is a shock, and I thought 'It got to be done, it got to be done' and I went out and I was with my best friend and when I came out of the doctor's office the counsellor was waiting for me with a coffee, she took my hand and we went to sit down and discuss it all over. She was there at the moment of the decision-making... I told her that I decided to go for the ovarectomy and she was happy about the fact that I made my mind up. (Jill)

At a different point in the interview Jill described again the counsellor's support at the same time of decision-making:

The doctors that were there explained to me both treatments, plus the operation - the ovarectomy and the effect that it would have: hot flushes etc... and the chemotherapy I knew... so I have decided on the ovarectomy... and I was to come back to [the hospital] after thinking about it at home and making my mind up which one I would choose... when I came out of the office the counsellor was waiting for me and took me to her office and said "have a cup of coffee" and she wondered, she asked if I was ready to accept... if I accepted having to go through another choice, and I said: "no, I wasn't ready to take a decision". It was at the wrong time. The

mastectomy was fine but making another choice so quickly... and again she asked if there was something I wanted to ask and she discussed both treatments with me, and I made up my mind then that I would go for the ovarectomy. (Jill)

Ruth herself did not feel in the need of counselling. However, when that topic was discussed in an abstract way she also thought that generally counselling was important at the decision-making points:

I think that this is the stage [when having to make a decision] at which you could do with the counsellors as well. You need somebody that knows more about it and yet has the time to talk to you... (Ruth)

Rose was given the option whether to join a trial that would randomly decide her systemic treatment. Before giving her negative decision to the doctor, she consulted the nurse counsellor:

I asked the counsellor. I asked the counsellor [what I should choose] before I have told Mr. D [my decision]. I didn't want to go to the surgeon before I was able to give him a final decision. I talked to the counsellor and she agreed with me that it is best for me to make my mind up than to feel I was being pushed into things which I didn't really want... Without the counsellor there was a chance that I could have been pushed into joining the trial - I would have felt 'I don't want to say no to Mr. D' whereas I could say to the counsellor 'I feel I can't go into the trial, I don't feel I could cope with it' and she understood. (Rose)

In Rose's case the counsellor protected her and acted as an advocate - making sure that Rose did not make a decision against her better judgement. Rose felt confident about telling the counsellor her true wishes and desires, a thing she did not feel free to do with the doctor. She could discuss things with the counsellor and still be indecisive as to what treatment she would choose, whereas she wanted to face the surgeon with a clear mind.

The timing of counselling seemed to be an important element as considered by the interviewees. They perceived counselling as an important potential source of support, especially in the early stages of the disease - immediately after hearing the diagnosis, and at the primary stages of decision-making concerning treatment. Nurses, and especially the specialist breast care counsellor nurse, should be, therefore, aware of the women's special needs for support at these points along the 'breast cancer continuum'. As one of the nurse counsellors summarised it:

> *I think that really this is when we're of most value - I think it's around about the decision-making time... (NC 6)*

Counselling as a Source of Explanation, Information and Advice

> *...the information that they're getting from the consultants and ourselves here, they get all the information that they need to know, there's certainly no holding back on information that's important. (NC 5)*

Information and advice were seen as important elements of the counselling relationship, especially at the time of decision-making. In some cases, much of the medical information was provided by the nurse counsellor and was better 'digested' after hearing it from her. The counsellor had both the time and the knowledge to go with the woman through various aspects of the illness, the treatment, and the related side effects.

Angela said:

> *I think she could help [at the decision-making process]. I am not saying she can make the decision for you but she might make the options a bit clearer. That helped to clear up the mind - your own mind. (Angela)*

According to Ruth's understanding adequate explanations can be particularly important for women who are in distress. They should, she thought, be offered counselling as soon as possible in order to reduce their anxiety.

> *...in fact I know that I am not a bothered person but some people were and I think they need to be seen [by the counsellor] faster and possibly have the explanations for things given. (Ruth)*

Rose suggested that the counsellor is also in the best position to explain the medical facts to the family, when the patient herself cannot do so.

> *...I should think that she'll [the counsellor] be able to explain better to the family than I could, a lot of medical things - the treatment. I couldn't explain the treatment bit, but the counsellor could explain to my husband all about the treatment and what would happen. (Rose)*

Rose also gave a specific example where she thought counselling could serve as a source of information and explanation, concerning the illness and the related treatment:

> *I didn't even know that you could have the implant put in - I didn't know there was such thing as artificial nipples and things like this, and I didn't need them, but for people who did, in counselling it would all be explained. (Rose)*

Lynn thought that the giving of information and explanation should be done according to the needs of the woman, and to her capacity to take in the information. She realised that the counsellor was able, in the time available to her, to assess how much and what type of information an individual woman would require. It is the personal contact that the counsellor has with the women, and the nature of the counselling relationship that makes this possible:

> *The staff at the hospital haven't got the time to get to know you personally quickly enough and that's where the counsellor perhaps comes in, she somehow seems to have an intuition, I think she was*

in a very short amount of time able to find out people's social lives and locate and take in information about, I don't mean intelligence, but their ability to understand and by the way they talk and the way they cope with the immediate situation she probably is the best able to know, to judge how much that person can cope with the disease and how much information should be given to that person. (Lynn)

Mandy expressed the expectation that the counsellor should have a sound medical background.

Well, I think you have to be something... I mean a counsellor has got to know what you're going through, what your operation is all about, she has got to know so she can talk to you about it. If you have got queries and you ask her... she has to have an idea about an answer, so I would say that you have got to have nursing experience to be a counsellor. (Mandy)

Also the nurses saw the provision of information as an essential element in the counselling relationship. As NC 1 said: "*I see the role of the counsellor as an information-giver...*". A similar statement was provided by NC 3: "*I would see my role as... information-giving...*".

At the time of decision-making specifically, NC 1 understood her involvement as:

Well... actively you try to ensure that the patient has all the facts and you often ask her to repeat the facts to you to try and ensure that she understood what decisions, what the alternatives are. (NC 1)

Again, similarly, NC 3 mentioned that:

Telling the patient that they have the choice is important. Giving them the information, as much information that they need or that they want to make that choice rationally. (NC 3)

NC 4 described her role as an information-giver in a somewhat more 'limited' way:

I feel my role is just explaining why they are given a choice and what the different choices are. Basically repeating in different words perhaps and different ways, what the surgeons have said and giving them a general picture about the treatment of breast cancer. (NC 4)

NC 5 summed it up as:

I see my job as being informative, about being able to give that information in lay terms that they can understand, because doctors tend to use technical language that they don't always understand. (NC 5)

Practical as well as emotional issues may be tackled through the counselling relationship. It is a form of knowledgeable and informed, as well as empathic, support. Support, I would argue, is the essence of this interaction. Rather than providing pure advice, which has been the more traditional understanding of counselling, it recently has become more associated with a personal, holistic form of support.

The Emotional Support Given by the Specialist Nurse Counsellor

The possibility to talk to the specialist nurse counsellor and to be counselled by her was seen by the women as an important source of emotional support. It was especially important for women who had little or no support from their family and friends. As Susan described it:

...some people are really quite depressed and need a lot of help from the counsellor... (Susan)

The women agreed that an important aspect of support that should be provided by the counsellor was her always being available. Some of the women appreciated the fact that the counsellor made herself approachable at any time. Jill described how the counsellor was always there, ready to talk to her:

She was there at the bedside always with a smile ready for a chat, ready to answer if you wanted to ask anything, if anything upsets you, any worries. (Jill)

Jill continued by saying:

On the day I was leaving the hospital after the ovarectomy, she was there. She was there after the operation to see me. Two days after. The morning she knew I was discharged... I was packing my bag, ready to leave, and she was there. She took time to come and she made the effort to see me before I left the hospital again, she gave me her home telephone number, the card about contacting her. So we had a chat... (Jill)

NC 5 also acknowledged the importance of her 'just being there' and available in providing support:

So just the fact that you're there sometimes helps, even though they [the women] don't necessarily approach you... (NC 5)

Ruth viewed herself as lucky since she had a lot of support from her friends, some of whom have also experienced breast cancer. However, she acknowledged the fact that some women do not have this support and are therefore in need of counselling.

I think I was really really fortunate to have had so many friends who went through the same thing... they were all very supportive, got in touch with me when I was in and sort of sent me flowers, phoned me immediately I was out and all that sort of thing... em... O.K. it's the people that haven't got that, that's when you need a counsellor. (Ruth)

Sandra also thought that for someone who does not have a supportive family, it is important to talk with the counsellor:

But if you don't have a family who are supportive, or if you can't talk to your family, some people can't talk to their family, or their family won't talk to them... One of my daughters can hardly mention the word, she doesn't seem to be able to bring herself to

accept the fact that I had cancer. But the other part of the family is very good. But I think if you haven't got a supportive family you need someone to talk things through with. (Sandra)

For Lynn the counselling in the form of support was extremely important, mainly because she did not have a family to rely on. The counsellor also gave her a great deal of practical help. An example of that practical help was the fact that the counsellor, after understanding Lynn's situation at home (being divorced and a single parent), arranged straight away for someone to come and help Lynn with the housework, once she was back at home after the operation. This was a great relief for Lynn who was worried how she would manage alone once she was discharged - taking care of her son, the household and herself, as well as a sick mother who lived alone. Moreover, Lynn saw something special in the counsellor apart from the practical help that she offered. Lynn explained that the counsellor had a unique ability to personalise the situation and to remember names of important people in her life. This made her feel a special individual.

And she took interest in [Tomy], she would refer to my son as [Richard] immediately, I think that is a great sign of a counsellor, the ability to personalise the situation.

...and she knew about [my new relationship] and was able to talk about him and and find out if he did help me and how did I feel about this, and how did he feel about that, and it was very good that she was able to remember names and bring my life in, ***it wasn't just talking about me, it was trying to see the whole life****. That was very helpful, that counselling. (Lynn)*

Some of the women and the nurses mentioned the fact that because the counsellor was also a woman, she could emotionally better understand women with breast cancer, than, for example, a male doctor:

I think it's quite important to be a woman because most of the medical staff tend to be men and I think women can relate better to me because I am a woman. You can understand a lot of the feelings they have which I really, no matter how good doctor men are, I sometimes think the men can't fully understand. They think they

understand, I don't think they totally understand what the females feel. (NC 5)

NC 6 described the same idea in a different way. In her words, the counsellor is able to get into what she termed the 'hurt bit', the real and even painful emotional aspects of things.

...they [the doctors] don't get into it, into the hurt bits of it, they try to keep out of the hurt bits altogether. But we allow ourselves to go into that hurt bit and maybe ride that hurt bit with them [the women] for quite a while. (NC 6)

She also argued that this is so partly because the counsellor is also a female. Furthermore, like Rose, she thought that it is the friendly element which builds the counselling relationship. The women need a friend to talk to - a friend in the health team.

I think they need a friend and I think that's what counselling is, someone to be there when they need you. (NC 6)

In conclusion, the following points were mentioned as important to successful counselling and support: identification of patients who lack support from family and friends, availability of the counsellor at all times, personal interest of the counsellor in the patient, her circumstances and special needs, and help in problematic matters beyond the narrow scope of medical care. A woman friend in the health team who can provide emotional support, was summarised by some as chracterising the counselling relationship.

Nursing and the Holistic Approach in Counselling

Trying to see the 'whole life', as Lynn described the counselling she received, is the meaning of the holistic approach which increasingly gained importance in the practice of nursing. Nurses, as described by Capra (1983) see themselves at the forefront of the holistic movement. This is

particularly true of counselling - the major form of nursing practice which should apply the holistic approach towards life in general and health and disease in particular. As NC 7 mentioned:

> *...the consultants are inclined to do their thing by seeing the treatment that is needed. They sometimes don't see the patient with all her problems that she has to cope with... where we can sort of look at that more. (NC 7)*

Capra (1983) a physicist by profession, wrote about the changes in science and society in the last two decades. He saw humanity as being at a turning point, shifting from mechanical notions to more holistic, even mystical paradigms. As an example Capra looks at medicine. In examining the change that health care is going through, he discusses the traditional role of the nurse, and the changes that nursing might be facing:

> Because of the narrow biomedical view of illness and the patriarchal patterns of power in the health care system, the important role that nurses play in the healing process through their human contacts is not fully recognized. From these contacts nurses often acquire much more extensive knowledge of the patient's physical and psychological condition than doctors, but this knowledge is considered less relevant than the M.D.'s scientific assessment based on laboratory tests. (Capra, 1983, p.159)

However, argues Capra:

> Increasing number of nurses are deciding that they want to be independent therapists rather than assistants to doctors, and are in the process of applying the holistic approach to their practice. These highly educated and motivated nurses will be best qualified to take on the responsibilities of general practitioner. They will be able to provide the necessary health education and counseling and to assess the patients' life dynamics as a basis for preventive health care... Ideally she [the nurse] would know her patient well... and would be available throughout the entire procedure, somewhat like a lawyer who guides a client through a trial. (Capra, 1983, p.369)

The traditional biomedical paradigm, therefore, has seen the body as a machine comprising of various parts, and disease and illness as a fault in the functioning of that machine. The doctors were the ones to repair that machine. This view has been based on the division between the mind and the body, or more generally the division between spirit and matter. However, this paradigm has been slowly replaced by the holistic approach to health and disease, and consequently to a shift in the practice of medicine. The medical profession has started to realise that there is a need to treat the person as a whole and not just the disease. The psychological consequences, physiological and sociological elements in a person's life are now more fully understood as inter-related to health and illness, and disease should, therefore, not be treated in an isolated manner. The idea of counselling is a product of that shift of outlook on health care.

An example for the shift in medicine towards a holistic outlook, stressing the significance of nurse counselling can be taken from the area of breast cancer. One of the leading surgeons in the UK specialising in breast cancer, Professor Baum, began to discuss the need of his breast cancer patients for counselling and psychological support already in the late 1970's. Together with a nurse he addressed in an article in the 'Nursing Mirror' the particular role of the specialist breast care nurse counsellor:

> The counsellor does not attempt to give advice but, with empathy and a non-critical judgment of the patient's fears and anxiety, helps to achieve a process of psychological self-healing, to speed up the natural coping mechanisms enabling the patient to come to terms with the disease, its treatment and the morbidity of such treatment. (Baum and Jones, 1979, p.38)

It is interesting to note that Prof. Baum, a surgeon educated under the biomedical paradigm, has given much of his career to developing the counselling services for breast cancer patients. It is, again, the realisation that clinical treatment, in the form of surgery, is not necessarily the whole answer to healing and well being.

Faulder (1991) provides a further example worth mentioning in this context. Dr. Vicky Clement-Jones was a young London doctor when she developed ovarian cancer at the age of thirty-two. When diagnosed, her

life expectancy was less than a year. However, her treatment proved effective and she lived for several more years. During these years of being a patient, her view on medicine was transformed. Through her own experience, and through talking to many fellow cancer patients, she realised how little professional support and information was available to the patient. She therefore devoted her final years to developing a holistic support association for cancer patients. This association, the BACUP (British Association for Cancer United Patients) which was founded in 1985, is voluntary based, and is today one of the main associations providing cancer patients with independent voluntary support.

Despite the increasing shift in medicine from the mechanical to the holistic paradigm, its application is still rare and the criteria for the corresponding counselling have not been clearly formulated. It is, therefore, important to understand the meaning of holistic support: its content, the expertise required for providing it, but most of all, its limitations.

The Education and Training of the Counsellor

Much was said, especially by the nurses, about the education and the training that a breast care nurse counsellor should have. In one way or another, all the nurse counsellors agreed that a person that is appointed to the post should have done an advanced counselling course. The following comment made by NC 1 is representative of what the others have said:

> *I think without doubt that anybody who is in the post of nurse counsellor should not just be a nice person. She should have had experience and done a counselling course... (NC 1)*

Furthermore, she stated that:

> *It's important that people that are employed as nurse counsellors should have done the breast care course... one of the breast care courses which incorporates a vast overview of the treatment of breast cancer, the implications, oncological implications, everything to do with the breast and some counselling as well. (NC 1)*

This view was strongly supported by NC 5, who thought that a national course was needed. She suggested that at the end of such a course a certificate would be provided, and that only when having this certificate could one be employed as a Breast Care Nurse Counsellor:

> *I do think that there should be a nursing course that we should be able to do. I think that if there is ever a specific course and a certificate at the end of it, or something like that, then I feel that you can be recognised to have that particular training and you're doing the job...*
>
> *It would be good for us if there was a national course that you did, that it was necessary to do it and that way the health board would have to fund you to do it...*
>
> *I think there should be a recognised training that we have to do and that way I feel that it establishes the post better. (NC 5)*

NC 5 suggested, therefore, that a proper recognised national course is a prerequisite for being employed in the job, and that the course should be funded by the health board.

NC 6 talked in a practical way about the setting of such a course. She also very much believed in the importance of a course, but thought that the main course that is at present available - the Marsden Breast Care Nursing Course in London - is too long and too far away. The course is six weeks long and she said that it is impossible for people like her to go to London and be off work for that length of time. She, therefore, had her suggestion:

> *...I think it should be a course that could be done like Open University, so that you could still go to your work, and you could have like an ongoing postal sort of training going on, and then maybe meet for a couple of days somewhere so that you can go to Manchester or maybe them coming up to Edinburgh, or go down to London for two days for your course to have an intensive all together...*

Both NC 5 and NC 6 made it clear in the interviews that they would like to see a course being established in Scotland, which would enable more local people to attend it.

An interesting finding that appeared when talking to the nurses, was that most of them (six of the seven) did not actually call themselves counsellors. The most common reason given for that was that they did not feel they possessed the appropriate qualification and training that would justify such a title. NC 2 made this point very clear in the interview:

> *Well, I haven't got an actual qualification in counselling, and as LF has said, unless you have you should not call yourself a counsellor. In some of her writings she's actually been quite critical of nurses like myself calling themselves counsellors when they have no right to. Maybe that has influenced me a lot in my decision of not calling myself a counsellor. (NC 2)*

Similarly, NC 4 commented:

> *I'm not a counsellor, I've not - I've done counselling skills within a course and these are fairly basic skills, ways of getting people to express their feelings, explaining things in a non-threatening manner etc... but I don't see myself as a counsellor. However, I might see myself as a counsellor if I went beyond what I'm doing now and did another some sort of counselling training... I think there are maybe some nurses who see themselves as counsellors who are not either equipped or qualified to deal with... NC 4)*

A somewhat different view was expressed by NC 3. She believed much more that it is the person behind the counsellor and her ability to communicate, rather than actual counselling training and courses, that made one qualified to do the job. However, she said, this does not mean that counselling courses are not important.

> *...there are some people you could sit down and probably would never open up to and it wouldn't matter how many counselling courses they had done, you would still possibly never be able to speak to them. And there are other people who will have never done a counselling course in their lives who will be able to communicate with somebody and enable them, just by the way they communicate, to open up...*
>
> *But yes, you probably do need to have some form of educating people or directing people or teaching people how to use the skills that may be there - or giving them the confidence to use them... The*

basis of communication and communication skills are probably much more important than in-depth psychological counselling (NC 3)

Being able to become a successful counsellor, therefore, is a natural inborn trait that someone may have or may not have, thought NC 3. She continued by saying that life experiences and maturity are also important:

I think you do need experience in whatever word we're caring to call it. If we're calling it counselling, I think a lot of that experience comes from maturity, a lot of that experience comes from life situations... (NC 3)

In a slightly different manner, NC 6 put forward a similar idea:

I don't think you should be too young, even though you are a good counsellor. I don't think you should be any younger than... 20-25... I think you've to be worldly-wise as well as professionally wise... (NC 6)

It seems, therefore, from talking to the nurse counsellors, that they all acknowledged the significance of appropriate training for the job. Their views about the matter were rather strong, and it may be explained by the fact that at the time that most of them were appointed to their present post, such courses were not yet established. Research evaluating the importance of such training has also only been published in recent years when these nurses were already well into their work. There is a certain element of regret felt by the nurses, about the fact that they may not have been trained or qualified well enough. Here are two examples of how the nurse counsellors talked about their 'missing' qualifications:

She [the nurse counsellor appointed to the job] should have done a counselling course. This is me who has not done a counselling course, but that was the way it was those days. (NC 1)

I think it is probably an essential thing to do [a counselling course]. Maybe my successor will have that qualification. (NC 2)

The Limitations of Nurse Counselling as a Source of Support

'Having Been There'

> *I know I haven't had breast cancer so I can't understand how a woman feels when she is told that... (NC 5)*

The main limitation of the counselling given to the interviewed women, as they described it, was that the counsellor had not personally experienced the disease. The women generally felt that someone who 'has not been there', like them in the same path of the breast cancer situation, could not really have the full understanding of the experience that is required to give truly helpful support. This was a limitation the counsellor had to recognise.

Susan shared the view that having breast cancer is a precondition for the ability to give good support. She said in our interview:

> *...as much as the counsellor is fantastic, she has not been through it, you understand? So if you've been through it you can then try and give a fair advice, because you know what these people are going through, because you have been in that path before... (Susan)*

She continued:

> *We all meet [the women that were hospitalised together] and we find that we now, if we meet together and discuss things we actually find that more comfort than having to go and look for the counsellor, you know, because we have all been there. (Susan)*

The counsellor, realising this, asked Susan to talk to a young woman who had just been given the diagnosis and was extremely distressed. This point was raised in the context of 'women to women support' but should be referred to again in the present context of limitations of nursing counselling.

> *I went in and this girl was crying, and I could have cried for her, because to be twenty three, not married, she wanted children and everything and she just was beside herself. I said 'there were days*

when... yes, I was a little bit down... but never too too bad' and I said 'the very first day I was diagnosed as having a tumour, yes I burst into tears but I think you come to terms with it' ***by the end of a half hour counselling, as the counsellor put it, me counselling this twenty three year old,*** *I had her laughing because I was telling her about all the fun we've had in the hospital, how nice everybody had been, the things that we've got up to that we weren't suppose to get up to, but we did, it's like being back at school - you're not suppose to do that thing but yet... and at the end of it she and her mother were both laughing. (Susan)*

The counsellor arranged in many cases for women to meet one another and discuss things, knowing that this can be more supportive than the help she could offer. As Sophie described it:

...it was a good idea to meet people [who also had breast cancer] like the counsellor organised, to say 'well, I have been through that, I know exactly what you are going through - yes, I felt like that as well...'. (Sophie)

The fact that 'not having been there' was a limiting element to the support and advice the counsellor could give, raised many questions which should be addressed. Can one give counselling without 'having been there'? Is there a real value to that counselling? That is, is there meaning and effectiveness to the advice given by someone who is conceived by the patient as an outsider who has no real idea of what they are going through? It could be asked whether we, as health professionals, are right in asking anyone to participate in decision-making when we have not shared their unique, frightening experience. It is a situation where professional knowledge can not be based on personal experience.

However, some other ideas were expressed by the women which suggested that it was actually easy to talk to the counsellor since, not having breast cancer herself, she did not get too personal and viewed things from a distance. Both Susan and Jill shared the view that the counsellor was distant in some ways, 'The counsellor did not get too personal' (Susan). They looked on it as a positive feature of the counselling relationship, something that enabled talking and enhanced the expression of emotions.

The fact that the counsellor was an 'outsider' and 'has not been there' was found by them to be helpful and positive, rather than a limiting factor.

Earlier work on oncology counselling, addressed this argument and discussed the idea of sharing the experience of breast cancer in relation to the qualifications needed by a counsellor working in an oncology unit.

> ...counsellors need appropriate help, support and training. It is not enough to choose the kindest nurse from the outpatient department who has had years of experience with patients with cancer and assume that she or he will automatically be an effective counsellor. Neither it is wise to assume that cancer victims will possess counselling skills merely by virtue of their experience of having the disease and treatment. It is imperative that these enthusiastic and often genuinely artruistic people should be interviewed carefully in order to establish not only their emotional stability but also their adjustment to their disease and general suitability as counsellors. (Fallowfield, 1988, p.728)

As has been discussed in the previous section, the qualities needed by an oncology counsellor in order to become successful, are connected with a high degree of professional and personal maturity. Though both long term experience of working with breast cancer patients, and having experienced breast cancer are important, they are not sufficient for practising professional counselling. Good counselling needs higher qualities than these experiences can provide.

Too Busy - Not Enough Time

Another limitation regarding the counselling they received, as expressed by the women, was concerned with the fact that the counsellor was extremely busy and occasionally had little time to spend with the individual woman. In the hospital there was only one counsellor employed in the breast cancer unit and she met almost every woman attending the hospital. She saw the women at the clinic, during the staging, at the time of hospitalisation, before and after the operation, and at follow up visits. The work load was extremely high, and as Sophie said:

Certainly the counsellor is very very good, she never rushes you, she is always interested, very very helpful, she is excellent, but they could do with more of her kind. (Sophie)

Ruth and Lynn shared the view that more counsellors should be available at the unit:

...it will obviously be worthwhile having more of them [counsellors] to provide the extra facility. I mean, with all my respect to the counsellor, I am not criticising her at all, far from it, but you know, she is always so busy. (Ruth)

I can see what hard work the counsellor does at that unit. She is in constant demand and all the open door policy as well, it's not only people who are being referred to consultation, but almost everyone should be contacted. She even gives you her home phone number which I felt was wonderful. (Lynn)

The experience of finding the counsellor too busy was shared by another respondent. Sandra found the decision-making an extremely stressful thing to cope with. On the day that the treatment options were presented to her, she tried to see the counsellor. She was very much in need of talking to the counsellor then. Unfortunately the counsellor was too busy and unavailable at that time.

I can say that it is a very hard decision to make, I didn't know what will be the best, and nobody has seemed to be able to advice me, so I thought, you know... I did wait to see the counsellor the other day that I was told about the options, but she was so busy that I went away...

I felt I needed to see her [the counsellor] that day [when hearing the treatment options], but I couldn't wait any longer, I think I maybe had enough of the hospital... you know, when you are waiting waiting and waiting... My husband was with me and he said we should wait to get in, but the lady before me obviously needed more counselling than me. (Sandra)

Also, after the operation, the women felt they needed a great deal of support and advice, but again, the counsellor was often too busy.

...but after the operation there are days when you really need to ask a bit of advice and I found the counsellor was too busy, you know what I mean? (Susan)

Having time for the woman is an essential element in the counselling relationship. The demands on the counsellor working at a breast cancer unit are extremely high and, therefore, often more than a single person is needed in a specific setting. The women in this research supported the view, that in many cases one counsellor did not have enough time to meet all the demands of each individual woman. Counselling, it can be concluded, is an extremely time consuming therapeutic interaction. However, it was interesting to note that none of the nurse counsellors in our talks mentioned that they did not have enough time to meet the requirements of their work. This may point to the fact that time is seen differently by the women, opposed to the nurse counsellors working in breast cancer care. An individual woman may feel that a weekly hour with the nurse counsellor is not enough time to discuss all her personal concerns, whereas for the nurse counsellor herself, spending an hour every week with the same woman will seem a great amount of time.

Using the Word 'Counselling'

...I think a lot of nurses call themselves counsellors or call the process of communication between themselves and patients as counselling - and I don't necessarily think it is counselling. (NC 4)

The word 'counselling' and 'counsellor' seemed to create a great deal of discussion and controversy. In the previous section the idea of being qualified to use this title was mentioned. It was mainly related to the training of the nurses. However, from the nurses' understanding in particular, it seemed that using the word counselling could also create a limitation as to the quality of the relationship. The women do not want to think they need 'counselling', thought the nurses. During my visit to NC 4 at her work, I noticed that there was no sign on her office door. When mentioning that to her, she said that she used to have a sign saying 'Stoma and Breast Care Nurse Counsellor' but that she soon realised that the women did not like to sit waiting in front of her office, since it identified them as being in need of counselling.

This idea, in a different way, was also expressed by other nurses:

> *...people up here I don't think really feel they should need counselling as such, and I think it's a word that tends to put the barriers up if you mention it. I think you can actually cause problems by mentioning the word 'counsellor' or 'counseling'. (NC 5)*

Many reasons were given by the nurses as to why using the word 'counselling' may inhibit the process of communication or the type of relationship developed with the woman. Here is how NC 1 understood this idea (it should be noted that NC 1 was the only one that used the word 'Counsellor' in her title):

> *...in some cases some people think of counselling as being in a punitive type of sense...*
>
> *...women hear the word counsellor and say "no, no, I don't want counselling", imagining I think, but again I'm maybe not correct in this, imagining that this person is going to sit down and talk great deeply to her and delve into her inner most soul. (NC 1)*

Furthermore, using the word 'counselling' may create some misunderstandings as to what the title 'counsellor' means. Breast Care Counsellor would be thought by some women to be connected to maternity and breast-feeding, said NC 3. Using only the title Nurse Counsellor would be associated with counselling nurses, thought NC 5; whereas NC 7 mentioned that Counsellors were understood by some women to be people who have been through the same experience before.

> *When my post was established I said I didn't want that title [of a Nurse Counsellor]... Some people saw Breast Care Nurse Counsellor as being involved with breast feeding... (NC 3)*
>
> *When we first started, Professor wanted to call us Mastectomy Counsellors, but not all women have a mastectomy, so they changed it to Nurse Counsellors, and people thought we counselled nurses. (NC 5)*
>
> *People think of counsellors a lot more as people who have gone through the same experience... (NC 7)*

NC 6, who was very direct in her talk, summed up the idea of using the word counselling by saying:

> *...but 'counselling' and 'counsellor' are two words I don't like... (NC 6)*

Summary

Six major topics were drawn out of the data in relation to the women's and nurse counsellors' view of counselling in breast cancer care. They talked about the importance of the timing of counselling, its being a source of information and advice, the emotionally supportive aspects of it, the holistic feature of counselling, the training of the counsellor and finally, its limitations.

The central question in this chapter is, 'what is the meaning of nurse counselling, as seen by the respondents?' Two main concepts seemed to be the key ideas behind this therapeutic relationship. The first is the concept of support. Counselling was strongly associated with the idea of support. This was especially so for women who had no family to rely upon, or little support from family and friends. The women and nurse counsellors were united in the view that effective counselling support entailed detection of patients in special need of support, frequent and long counselling sessions, availability of the counsellor at all times when support is acutely needed - especially at the point of diagnosis and decision-making, support in non-clinical matters, and, in some cases, support for the partner.

The other concept related to personal experiences with the disease. The path of breast cancer and the decisions involved seemed to be unique, something which those who 'have not been there' cannot **fully** understand. The nurse counsellor 'has not been there' which in several respects was a limiting factor to the support she could provide. The support that the women could give one another was at times more valuable than professional support. Still, some of the women and the nurses saw the 'distant' position of the counsellor who 'has not been there' as an advantage. By being an 'outsider' the counsellor can maintain objectivity and rationality which are important to the therapeutic process.

The ideas of nurses as counsellors was also discussed. The following words of the women best summarise this idea:

> *They [nurses] would make the best counsellors, they're experienced. (Mandy)*
>
> *I think the nurses should do the counselling... (Ruth)*
>
> *They [nurses] have the experience don't they? And they are able to back up and say "Well, we had patients before you like that and they are doing very well..." so I think they should do the counselling. (Sophie)*

Nurses were found to be the preferred group to provide counselling due to their medical and clinical experience. However, appropriate specialised training and education is necessary in order to prepare a breast care nurse counsellor for her most demanding role. Furthermore, the nurses are also more likely than doctors to get close to the women and communicate with them on a personal level. Being themselves women, the nurses can provide the possibility of a private and even intimate discussion.

Chapter IX:

MY EXPERIENCES IN THE RESEARCH

Introduction

In this chapter some of my personal experiences while doing this research are described. Without this personal dimension, I argue, the research would not be a truly phenomenological one. According to the phenomenological approach, the researcher's personality and experiences are an intrinsic part which must be taken into account and further described. In the present work, this is of special importance. The study has examined by a series of interviews the requirements breast cancer counselling should fulfill as reflected in the **lived world** of women with breast cancer, and the experiences of nurses working as counsellors in breast cancer care. The participation of the researcher in the study, therefore, has a special significance that should be examined. On the one hand, the researcher has affected the findings by her method of selection of interviewees, her active participation in the interviews, and her analysis of their content. On the other hand, the researcher herself has been affected by the intense confrontation with breast cancer, and the personal stories of patients and nurses. An evaluation of the **lived world** of the researcher as regarding this confrontation, may give insight into the psychological pressures acting on a breast care counsellor, and the special demands she may be facing.

This chapter is divided into two parts. In the first part, I will discuss the experiences I had, specifically at the stage of interviewing - the collection of phenomenological data. In the second part, I will describe the effect the study had on me as a person. Here, I will concentrate on the effects that may characterise the psychological pressures acting on counsellors in oncological breast care.

The Experience of Interviewing - Access to Data

The process of interviewing was the most intense experience during the research act. In the following section I would like, therefore, to reflect upon it and share it with the reader. In the context of this discussion, interviewing will be referred to as 'access to data'.

The term 'access to the data' means the ability to collect valuable and meaningful data, as defined by the objectives of the research. In this study, access meant entering the **lived world** of the women and nurses who were interviewed, and being allowed to learn about their experiences of the disease and the decisions on treatment. The topic of breast cancer and its treatment is clearly a difficult one involving issues of a very private nature such as body image, feelings of femininity, and sexual identity. The Scottish women (and here I refer to both breast cancer patients and nurse counsellors) who were interviewed were, at least initially, rather reserved. However, in order to develop a phenomenological understanding of their experiences, such access had to be achieved. Access to the data can be seen as being comprised of several layers. The deeper one enters into the data, the greater is the level of understanding which may be achieved. Many factors may prevent the possibility of doing so. The main factor that prevented uncovering all the layers of data in this study was the intimate and private nature of the topic studied. This meant that when interviewing the women with breast cancer, I often had to avoid sensitive questions, such as those relating to marital relationship and sexual life, in order not to intimidate the woman concerned. Some valuable information might have been lost by this, but I was satisfied that the dignity and well being of the woman was maintained. At times when a sense of frustration was experienced arising from not being able to gain 'deeper' data, I had to remind myself that my object was not to cause any distress to the woman.

Access to data, in the case of the interviews with the women and nurses, could further be hampered by my inability to facilitate the openness of an interviewee. An example for this was my interview with Sandra (see Appendix 4).

From the beginning of the interview with Sandra I realised that she was more distressed than any of the other women I had spoken to. She also mentioned the difficulty that she faced in confronting the disease and the decisions regarding treatment. It seemed that she was under a great deal of pressure. It was hard to uncover the layers and understand why Sandra found it all so very difficult. Sandra chose to talk little and rather vaguely. I felt that the **real** issue was left unsaid. Attempts to ask her about her family and social support, about whether she knew other women with breast cancer, revealed very little and could not explain why she was so distressed. Even though she found it hard to talk, Sandra expressed the need for support; it seemed that she was almost crying out for some sort of help. She asked a lot of factual questions and wanted to hear things from me that would reassure her.

In my summary of the interview I wrote:

> Sandra's questions were challenging and I felt she deserved a precise and honest answer. The first question was relatively easy to handle, but the second one was far more difficult. I could not tell her what I would have chosen had I had the same options concerning treatment, for two main reasons: 1) I did not know! and 2) It might have influenced her if I did give my opinion. I 'escaped' from answering these questions by telling her what the literature said and by trying to reassure her a bit. At the end of our meeting we discussed the possibility of Sandra going and meeting the nurse counsellor again. This situation was an example of a problem one might face in a qualitative research interview which is unstructured. The two forces that were leading in such a sensitive interaction were that of the interviewer wanting to get as much data as possible for further analysis and for the sake of the research. On the other hand that of the interviewee who was in need of counselling, advice, support and information. I clearly did not want to get into a counselling relationship with Sandra, but mainly wanted to get relevant information. But I also could not leave her with a feeling of frustration and confusion. It is a delicate path to find in the middle, and I can only hope that I have somehow managed to find it for this specific situation. It is probably impossible to find this 'ideal' path. However, being aware of the sensitivities and difficulties involved was by itself of great importance and value for me. (From the paper on the interview with Sandra).

Sandra received the transcript of the interview like all the other women. She has send it back to me with the following comments : "Thank you again for your time and patience with me - how I wish I had been a better interviewee! - maybe I was a bit nervous. Next time I shall speak up." This demonstrated how difficult it was for some women to talk about such sensitive issues.

In general, I could not raise direct questions such as about the sexual life after mastectomy that the woman was not ready to discuss. Questions such as these can be asked only if and when the right relationship between interviewer and respondent has been developed. Entering the private life of a participant must be done only when one is invited to do so. In some of the interviews an invitation was received while in others not. The object, however, was to develop a relationship which would encourage the woman to discuss true and personal experiences related to her illness and the decisions regarding treatment.

When interviewing the nurse counsellors, also a great sense of sensitivity needed to be applied. This was due to two main reasons. The first was the nature of the topic that was being discussed. Breast cancer threatens every woman, and the nurse counsellors were not immune against this threat in any way. One could even say that because they were dealing with it on a daily basis, the threat became for some of them very real. The other reason was the professional one. It was me as a researcher wanting to get information from them, and not the other way round. It was not uncommon for some of them, however, to ask for information from me, especially an academic type of information. I tried to make it clear to them that it is their years of experience that I am interested to learn about. A discourse between two professionals, and all that it entails, may add a delicate element to such a research type of interaction.

The experience of interviewing was probably the most profound in the course of the study. Being engaged in a conversation with these special Scottish women (both patients and nurses) has had a great impact on me. However, there were several difficulties that had to be solved in order to enable a smooth process of interviewing. First, there was the cultural aspect. Being an Israeli, I was used to a rather direct manner of

communication. I was somewhat anxious that this might create a problem when approaching the Scottish women, whom I expected to be reserved. However, most of the women I met were quite lively, open and direct in their expression. We could, therefore, generally communicate well.

Coming from a different culture has added an interesting perspective to the interviews. All the women, as well as the nurses, were interested in my background and asked questions about it. For example, it was common for them to ask about the situation of breast cancer and the available treatment in Israel. Answering such questions proved to be a good way of introducing myself and my project, and of entering into the interview itself. The 'small talk' about where I came from and what brought me to Britain, provided an excellent opportunity to get closer to the woman or the nurse and create a comfortable atmosphere for discussion.

Another problem which I experienced while interviewing was the language barrier. English is not my mother tongue and 'Lowland Scots' even less so. There were times when it was difficult for me to understand what the woman or the nurse was saying. This can be demonstrated by the following somewhat extreme example. When transcribing the group meeting (which mainly involved a discourse of the women between themselves), I tried to keep as close as possible to the Scottish dialect and transcribed it phonetically. At one point Lucy said:

> *As ah say, we're talkin aboot experiences... in ma work everybody knew, I telt the boss tae tell them aw there's only twenty o us work well only one person oot a there treated me wrong I think, and everybody else was fine but it a wee dick in charge a us and he couldnae look at me an ah used tae say tae the ladies, "Ye ken - I feel as if am an outcast." (Re-Meeting)*

Age was another issue related to the experience of interviewing. The women I talked to were mostly in their late fifties or sixties, and so I could have been closer in age to their daughters. The nurses were also much older than myself and had many years of working experience. Conducting such interviews at a relatively young age meant that I had to confront

certain topics, such as the threat from mutilation and death, in a way which was new for me. It was, therefore, difficult at times to deal with some of these issues and know how to react to them during an interview.

Experiences of the Researcher as a Subject

As pointed out earlier, in phenomenological study the researcher is an integral part of the human interaction that serves to accumulate the data. She influences the communication process of data acquisition and is affected by it. Therefore, the experiences of the researcher during the research has important implications for the study. Revealing these personal experiences can give further insight into the examined phenomena.

The major experiences I have made during this work can be classified as those made at the early stage, during the interviews, and following the interviews. The early-stage experiences included my moving to a foreign country (UK) to conduct the research, becoming familiar with its culture, learning the psychological and nursing background of counselling, and acquainting myself with breast cancer and breast cancer care.

During the interviews a specific experience was the projection of the reported phenomena of breast cancer on my body and person. This will be discussed in the following section.

Personalising the Experience of Breast Cancer

The topics discussed in the interviews and what the women and the nurses said had a clear personal and even intimate effect on me as a woman. I was confronted with ideas and thoughts about feminine identity, and the importance of the breasts under the very real perspective of losing both. It was not unusual for me to find myself thinking during the interviews 'what would I have chosen had I had breast cancer and was given options concerning treatment?' I am not sure that I have an answer to this question. 'How could I possibly live without my breasts?' I thought, and 'would any man ever like me with only one breast?' On the

other hand, I asked myself 'how could I be at peace knowing that there might still be cancer cells left in my body?' I needed to get answers to these questions and was frustrated at my inability to reach any reliable one. Being a nurse did not help. There appeared to be little rationality involved when considering the case for yourself. How can we expect a woman to make a 'rational decision' concerning herself without the appropriate help and support?

The idea of having cancer increasingly frightened and concerned me also in my private life. Twice in my dreams I had the disease and in both cases it was a devastating experience. In one dream, I was horrified at having to undergo bilateral mastectomy. I kept on checking my breasts at an exaggerated high frequency. I came to realise that I am at high risk of developing the disease. I am Jewish, over-weight, have not given birth yet, and am also single. My grandmother died of cancer of the stomach. Consequently, I evaluated my emotions and discerned the real situation of being healthy from the understanding I was gaining of the mental processes women with breast cancer probably go through. I believe that I now know better what it can mean to be obsessed by the idea of this disease.

The Confrontation of the Counsellor with Breast Cancer

My interaction with the women who participated in the research may have been similar to the interaction of a breast care counsellor with her patients. The two major differences lay in the frequency of the interaction and my role in them. Whereas I was confronted with the narratives of the breast cancer experiences only at large intervals, the counsellor is constantly confronted with them. In my role during the interviews I experienced a conflict between my position as a researcher and my professional instinct as a nurse. As a nurse I desired to help the women with some counselling, advice and support. However, as a researcher, I had to refrain from doing so. In contrast, the essence of the counsellor's interaction with the patient is the counselling process.

The impact the interviews had on me may have some implications concerning the psychological pressures the breast care counsellor should

learn to deal with in order to effectively practice her work. The counsellor stands the danger of personalising the situation of having breast cancer. When this happens three psychological reactions are possible: the counsellor may identify herself with the women to the point where she 'suffers together with them' and loses the ability to support them. Alternatively, she may avoid the reality of cancer and distance herself emotionally from the women, lose her empathy for them and her ability to support them. The third possibility that constitutes the only productive attitude towards the disease and the patients is the vigilant reaction. The counsellor learns to use her emotional reactions to the disease for gaining insight into the **lived world** of the patient while avoiding personalising it.

In view of these considerations, it may be concluded that a nurse counsellor who aims to support women with breast cancer must first expose herself to the breast cancer experience. She should undergo an active process of self exploration in order to determine her ability to cope with the demanding situation.

Summary

My own experiences while doing this study were an integral part of the research process. Being a dialogue with the women and the nurses, the work constituted mutual interaction of our personalities. It was me: a woman, a nurse and a researcher who took part in the course of this work. It would probably be wrong to state which of the three had the most dominant effect on this study. It was rather their combination. This has made the experience unique and valuable. It was a special opportunity for self expression as a woman in the context of a systematic investigation in the field of nursing.

Interviewing, which was the process of data collection and which meant a human interaction in a research situation, was a most valuable experience. It was the actual discourse with women with breast cancer and with nurse counsellors that care for them, that formed the basis for

this work, and which left a great impact on the researcher as a woman and a nurse.

In this study I recorded the experiences of breast cancer intensely and occupied myself with their evaluation. Consequently I entered the process of personalising the experience of breast cancer. I had to analyse the psychological problems involved and their effect on me as a person and on the research. This may be seen as analogous to the situation of a breast counsellor, especially a beginning one. The need to prepare a candidate counsellor for this impact of the disease, and the means for doing so, may be inferred from my own experiences.

Chapter X:

DISCUSSION

General Comments

This work is about nurse counselling and support for women who have been given the diagnosis of breast cancer. In order to get an understanding of what counselling means, a descriptive/qualitative study has been attempted, with the aim of gaining an insight into the experiences of women who are confronted with the disease. The method chosen was based on the phenomenological line of thought - trying to enter the 'lived-world' of individuals as related to every-day life situations. Interview transcripts with women with breast cancer, and nurses working as counsellors in breast cancer care, provided the raw data on which analysis was based. The concepts and themes which were extracted and isolated gave the possibility for further interpretation. The insight which was gained provided a deeper understanding of some common ideas and trends as related to the experience with the disease. Because of the specific nature and setting of the study, generalisations cannot be made, or made with much caution. Conclusions from the findings are therefore best understood as descriptive rather than prescriptive.

In order to enter the experience of breast cancer, it was decided to focus on a common aspect related to the confrontation with the disease, namely the decision-making process. Decision-making served as an entry door to learn about 'what is it like' to be a woman with breast cancer, who in the light of the diagnosis has to face not only herself, but also her family, friends, and the health care team. Decision-making is a continuous process along the breast cancer path. What to tell the partner? how to re-organise life responsibilities and how to face the male doctor are just but a few general issues that a woman may have to decide upon. In this study the decision-making regarding treatment provided the main area of concern.

The possibility for women to take part in decision-making concerning their treatment is a relatively new development in breast cancer care. Modern advancement in the medical treatment of the disease opened the door for many methods of therapy to be applied, such as chemotherapy, radiotherapy, and hormonal therapy. These developments regarding options of therapy left women more confused about their treatment than ever before. The choice between mastectomy and lumpectomy plus

radiation is probably the most extreme example, but other choices may involve adjuvant therapy, joining medical trials, and methods of breast reconstruction.

It is argued here that giving women the possibility of taking part in clinical decision-making gives them the opportunity to exercise power and control over decisions that have a major effect on their lives. This does not imply, however, that responsibility should shift away from the health-care team. It is a situation of shared responsibility and control. The health care team must take responsibility in assisting the woman throughout the decision-making process by providing her with information, explanation, and emotional support, which are all tools for managing such a complex situation. This is where nurse counselling and support can be applied. In this work, it is being argued that nurses are in a preferred position to provide women with many aspects of counselling - whether informative, supportive or directive. The leitmotif of this study is women's emancipation, empowerment and control. Its relation to nurse counselling will be further elaborated.

The structure of the following chapter follows the general structure of this thesis. First, there is an exploration of the issue of participation in the decision-making regarding treatment, and then the role of nurse counselling is examined. It is only through understanding the experience of breast cancer and the decisions involved, that an insight into our supportive nursing role may be gained.

In the present chapter, the findings of the study will be discussed and related to relevant existing literature in the field. Issues concerning the application of nurse counselling will be drawn, and suggestions for further research given. Three sections will comprise the chapter:

- Participation in Treatment Decision-Making
- Nurse Counselling and Support
- Applying the Nurse Counselling Role

Participation in Treatment Decision-Making

Three different social realities were analysed as experienced by the women in this study in relation to their participation in treatment decision-making. These social realities were: the **Self-World**, the **Relationship with the Doctor**, and the importance of the **Network of Support**. Twelve themes which evolved from the interpretation of the interviews demonstrated a social process. In the beginning, the woman's Self-World - that is her unique personal world of experiences - confronts the doctor who presents the initial diagnosis and options for treatment. This situation may be seen as threatening and as invading the Self-World. The inner equilibrium is shaken. In the next stage, there is the use of the available network of support, which provides a means of returning to and regaining the stability of the Self-World. The network of support was comprised of family, friends, other women with breast cancer, and the health care team. During all this process the woman and her Self World are at the centre - having to confront the diagnosis of breast cancer and the decisions involved. The specific themes that demonstrated this social process were fully described in chapter seven. In this chapter, a broader and more general discussion on issues related to participation in treatment decision-making will be provided.

A review of the psycho-oncology literature on decision-making in breast cancer care revealed that the following main questions were addressed:
- Who are the women who want to take an active part in the decision-making? What is their personality, family background and health history?
- What is the psychological benefit of participating in the choice of treatment?
- How do women go about making the decisions?
- What factors affect the decision-making? and, what treatments do women most commonly choose?

In the following sections the findings of the present study concerning each of these areas will be discussed in connection to the existing relevant literature. It should be noted, however, that these issues are closely related, and therefore it is not always possible to make a clear distinction between them.

Which women wish to participate in the choice of their treatment and exercise control, and which prefer the choice to be made for them? Both the women and the nurses in this study suggested that the factors that determined the women's preferences appeared to be related to a complex set of variables. On the one hand, there were the personal attributes which made every woman different in her general attitude towards participation in decision-making, and consequently in her willingness to share control in the choice of her treatment. There were also cultural, social, and even political, influences which may be unique only to a certain group of women, such as the women who took part in this study who shared a common background. Generalisations can, therefore, not be made. On the other hand, women share some common issues of concern just by the fact that they are women. These issues relate to their reality as women in a male dominant world.

The present study showed a similar pattern to that found in a study undertaken by Sloan and Degner (1992). They compared people who had been diagnosed as having cancer with a group of people without such a diagnosis, with regard to their wish to participate in the decision-making about their treatment. Their main finding was that people who had been given the diagnosis of cancer were seeking less control in clinical decision-making than that which was desired by undiagnosed people. Being diagnosed with cancer, therefore, has a negative effect on the wish of people to participate in the choice of their treatment.

The women in this study presented an ambivalent view. They generally talked about wanting to take part in the decision-making process. However, when the actual time of choice came, they were happy to leave the decision with the medical team. Control was directed away from the woman back to the doctor. Still, some of the women described such a situation differently, emphasising that they **chose not to choose**. By saying this, they meant that they still exercised some element of control.

The interaction of the women in the present study with their physician during the process of decision-making could be described as 'Guideline-

Cooperation' (Schain, 1989). In the 'Guideline-Cooperation' type of interaction the patient is alert, adult, and capable of rational judgement. However, while this type of interaction allows for dialogue and the patient is given the opportunity to demonstrate intelligent choice, the physician is still viewed as the ultimate authority. This type of communication encapsulates the widely expressed theme expressed in the interviews of the present study which was defined as: 'The Doctor Knows Best'. Schain (1980) further suggested 'Mutual Participation of Shared Responsibility' as the more advanced type of interaction. This type of interaction is designed to reinforce the qualities of the patient, while preserving a high level of regard for the skills, opinion, and expertise of the physician. According to this concept, the physician helps the patient to help herself. None of the accounts of the women and the nurses in this study would fit with such an advanced interaction between the women and the doctor. Schain Acknowledges, however, that: "This type of joint participation would not be appropriate for all patients, particularly not for those of very low intelligence and those who are emotionally inhibited from using their rational or cognitive skills to make sound judgement" (Schain, 1980, p.1037).

Overall, the findings of this study would support the conclusions made by Deming (1988), that women's desire to make decisions regarding their treatment should not be over-emphasised.:

> Theoretical studies conducted to ascertain how <u>much</u> active participation in medical decisions people desire (Vertinsky et al. ,1974 ; Cassileth et al., 1980), may tend to over-estimate the strength of this desire, especially in individuals who must grapple simultaneously with the shock of a frightening diagnosis, and with a demand to evaluate highly complex medical information under fairly extreme time pressures. (p.158)

Women vary in their wish to take part in breast care clinical decision-making. This study, however, demonstrated that women from a similar Scottish background were likely to share a common attitude concerning this issue. They tended to possess a more traditional way of dealing with health care situations, which was based on a patriarchal system, where the doctor is the one having the power and control. The diagnosis of breast

cancer itself may have an additional inhibiting influence on the women's desire, or even ability, to practice their 'right of choice'.

To conclude, personal and cultural factors seem to play a role in the desire of women for control. It is important, therefore, to assess the woman for both her individual as well as her social values. This should preferably be done before the woman enters into the process of decision-making. It will further be argued that counselling by a nurse provided the best opportunity for carrying out such an assessment. Moreover, I would suggest that as patients' advocates, nurses are the ones that can ensure that it is the woman's **right** and not **obligation** to elect her own treatment.

The Personal Benefits of Choice

Is there personal benefit associated with participation in the choice of treatment for women with primary breast cancer? Overall the findings of this study, arising from what the women and nurses have said, indicate a positive answer to the question. The respondents generally stated that having an opportunity to participate in the choice of treatment was of significant benefit to the subsequent coping with the disease and its treatment, and to a general psychological well being. Commonly, the women and nurse counsellors thought that such a choice should be given. These arguments, however, must be used with some caution. The nurse counsellors, in addition, also thought that some women may perceive the choice as a burden and as creating unnecessary stress.

Some studies have tried to evaluate the psychological benefit of patient's participation in decision-making about their treatment. As an example, a study done by Fallowfield et al. (1990) evaluated anxiety and depression in women with breast cancer. They examined women who were treated by three types of surgeons: those who offered a choice, those who preferred mastectomy, and those who suggested lumpectomy as the surgical treatment for their patients. Their study demonstrated that women seen by surgeons who offered choice whenever possible experienced less psychiatric morbidity, but that the benefit was not restricted to those women choosing treatment. "Choice" surgeons gave all women - choice or no choice - more adequate information.

Leinster, Ashcroft, Slade and Dewey (1989) also examined the benefit of choice and the different psychological adaptations to both mastectomy and lumpectomy. In their study, women with early breast cancer were offered the choice of mastectomy, lumpectomy plus radiotherapy, or entry into a trial in which the allocation to either type of treatment was randomised. Few women chose the trial, and most of them were relieved that a choice was available. They, therefore, demonstrated as well the benefit of choice and that tailoring the treatment to each woman's preference resulted in lower psychological morbidity.

In the present study, an interesting trend was found. The women were generally in favour of being involved in clinical decision-making. They mentioned that they were more happy and relaxed since they had had the opportunity to discuss their treatment options with the doctor. This is irrespective of whether they actually made the choice themselves, or left it with the medical team. They wanted to be informed and feel that they were taking an active part in the planning of their care. However, the nurse counsellors had a more ambivalent view of the matter. They thought that presenting women with the options concerning treatment might create confusion and provoke additional stress. It seemed that they wanted to protect the women from this burden.

It may be said, therefore, that giving women the opportunity to choose their own treatment would help them to cope with the diagnosis and the consequent therapy. One cannot assume, however, that every woman would actually benefit from exercising this choice. Here again, early assessment through counselling may help to identify those women who will most clearly benefit from going through the decision-making process, opposed to others who may experience it as a burden and as an unnecessary hassle.

Patterns of Decision-Making

Some studies have tried to address the question of 'How do women go about making the decisions?' Pierce (1993), for example, described three types of decision-making styles used by women with breast cancer: Deferrers, Delayers and Deliberators (which were more broadly discussed

in Chapter 3). These varied in the amount of, and time spent for, information-gathering, the number of alternatives considered, and the use of sources of support. Most of the women in this study belonged to the decision style group which Pierce (1993) defined as 'Deferrers'. She said that: "Subjects in the Deferrer decision-group appeared to be influenced by the salience of a particular alternative, which allowed them to make quick, conflict-free decisions. They frequently selected the alternative recommended by the physician, deferring to his or her expert judgement..." (p.25). The above description of the women's pattern of decision-making was further supported by the nurse counsellors when they discussed this issue in relation to the women they cared for.

The personal differences between women in their attitudes towards participation in the choice of treatment were also related to their coping mechanisms. Janis and Mann (1976), in their general theoretical model of coping with conflict (see figure 1, Chapter 3), described five different coping patterns, of which 'Vigilant Coping' was the most effective and was likely to lead to the most adequate decision. Vigilance was defined as a coping pattern by which "...the decision-maker searches painstakingly for relevant information, assimilates it in an unbiased manner, and appraises alternatives before making a choice" (p.658). None of the accounts of the women in this study, concerning their experience of decision-making, would fit with what Janis and Mann (1976) described as 'Vigilant Coping'. There was not much search for information and evaluation of alternatives, but rather the recommended course of action was taken. Ruth was the only exception in that respect. She used a more vigilant pattern of coping in her decision-making, although this primarily concerned the participation in clinical trials, and was associated with guilt feelings about her independent choice. Thus, the women were dependent on the doctor's advice, and predominantly used the type of coping that Janis and Mann defined as 'Unconflicted Change'. According to them, this is the type of coping where the decision-maker adopts uncritically whichever new course of action is most salient, or most strongly recommended, to him or her.

Decision-making is a highly complicated mental process. The cognitive steps which are used when making a choice vary from one person to

another. For the more vigilant decision-makers, detailed information provides the tool for making the decision. It is crucial, therefore, that women get the right amount of information which they require for making the decision. Since information provides the tools for decision-making, these two concepts cannot be separated. Information-giving as an important element of nurse counselling will be discussed at a later stage of this chapter.

Factors Influencing the Decision-Making

A variety of factors were identified by the women as influencing their decision-making, or attitude towards the decisions taken for them. These factors included internal and external variables. Internal factors were related to the personal inner world of the woman, such as her feelings towards her breasts and her idea of cancer as a life-threatening disease. External factors were connected to the influence of family, friends, the health team, as well as the coverage of the topic in the media. The distinction between external and internal influencing factors, however, was not always clear cut. The reason for this was that external factors, such as the influence of the family, may strongly affect internal factors such as personal beliefs, values and attitudes.

As described in some studies (e.g. Owens et al., 1987 ; Leinster et al., 1989 ; Margolis et al., 1989), women who attached considerable importance to their feelings about body image and outer appearance, might be devastated by the idea of a mastectomy and, therefore, were pleased to have the possibility of conservative surgery. Others who saw the threat from cancer and death as the important factor, were not satisfied at 'just' having a lumpectomy done and thus chose mastectomy as their preferable surgical treatment.

The majority of the women in the present study belonged to the latter group. They were more concerned about having their cancer removed than preserving their body integrity. The women expressed the view that having their breast removed was less difficult to cope with than with the threat of cancer and death. 'If you have a lumpectomy done you might never be at peace of mind', they said. A similar view was expressed by the

nurse counsellors when they described the women they cared for. This was consistent with the findings of Wilson et al. (1988) who in a large study demonstrated that when given a choice, more women would choose mastectomy than the conservative form of treatment.

Furthermore, in the light of past evidence and the findings of this study, it may be argued that lumpectomy, the more modern conservative treatment for primary breast cancer, does not necessarily protect the woman from psychological distress and morbidity (see, for example, Sanger and Reznikoff, 1981 ; Wolberg et al., 1987 ; Morris and Royle, 1987 ; Margolis et al., 1990 ; Fallowfield et al., 1990 ; Omne-Poten et al., 1992). On the contrary, some women might find that having a lumpectomy leaves them extremely worried about the consequences of the disease in the future, especially about the effectiveness of the treatment and the possibility of malignant recurrence. In this study Sandra provided an example of a woman who expressed such worries. These women need no less support and counselling than those who had a mastectomy performed. It is important, therefore, that nurse counselling of women who have a lumpectomy should not be neglected. The expression often used by the health team such as "she had **just a lumpectomy** done" should be avoided. '**Just a lumpectomy**' does not exist. These women who had a lumpectomy have in addition to coping with the surgery a constant threat of cancer, death, and further mutilation. This does not suggest that lumpectomy would not be suitable for women who would wish to preserve their breast, but rather that the psychological needs of these women should also be strongly recognised.

In conclusion, it is evident that there are many factors that influence women in their decision about their breast cancer treatment, and that these factors vary from one woman to another. Since these factors are individual, a nurse-counsellor should explore them together with the woman herself when attempting to support her throughout the decision-making process. The psychological effect of the decision seems to be more connected to the fact that the woman had some influence and control in the decision-making process, rather than to the actual type of treatment elected.

Nurse Counselling and Support

Counselling was seen as a special form of support. During the decision-making about treatment and the related social process, counselling by a nurse served as an important element of the Network of Support. It helped the women regain their stability of the inner Self-World. Four elements of counselling were identified in the interviews as particularly important to the patient. These were: giving information and advice, providing emotional support, preventing the woman from being alone, and introducing her to others who are experiencing breast cancer. Furthermore, the effectiveness of the counselling relationship was influenced by several factors which included:

- The Provision of Information.
- The Timing of Support.
- The Support Women with Breast Cancer Give Each Other.
- The Training of the Counsellor.

Each of these will be discussed in turn in the following sections.

The Provision of Information

For the women in this study the provision of information seemed to be an important component of counselling. The nurse counsellors themselves also stressed in the interviews that the provision of information is a central element of their counselling role. Since the confrontation of breast cancer involves many uncertainties, it was found that information, and particularly reassuring information, was a main source of support because it allows the woman to overcome many of her agonising fears. The desire for information, however, can vary and is an individual matter. One woman, like Ruth in this study, may wish to receive as much detailed information as possible, including diagnosis, treatment and prognosis. Another woman, having the same diagnosis, would want only very limited information and would therefore be satisfied with knowing only basic and general facts. Lucy and Sophie were clear examples which demonstrated such an attitude. It is of great importance, therefore, that the amount of information offered to a specific woman is properly adjusted to her needs and desires. Psychological harm can be done to a woman who

can only cope with very little information by telling her everything about her illness. Such a woman may be using denial as a coping mechanism, and by getting 'unwished-for' information might lose her ability to deal with the disease. On the other hand, a woman who wants to know a lot about her illness and treatment and is deprived of information might also be exposed to psychological morbidity. Other women may simply lack the background or frame of mind for comprehending and dealing with it. It is the woman's basic right to get only the appropriate and desired for information.

The idea of adjusting the quality and quantity of information given to a woman to match her expressed wishes and needs was widely expressed in the interviews. This is not consistent with the findings of Cassileth et al. (1980). They conclude their study on information and participation preferences among cancer patients by stating that:

> Clinicians often are concerned that providing patients with detailed information about their disease may create despair. It is useful to know that helping patients become well informed does not create depression but actually assists many patients in sustaining hopeful attitudes. Benefits associated with becoming knowledgeable and actively participating in one's care substantially outweigh the theoretical disadvantages of receiving potentially frightening information. (Cassileth et al., 1980, p.835)

In the light of the present study, I would suggest that providing information should not by itself serve as a major objective or ideal. It is the sensitivity towards the receiver of that information that should become our centre of concern. Information should be seen as a subjective means for coping rather than as an objective method or tool.

In this study, the women were generally satisfied with the information given to them. They all related it to the fact that they were given the opportunity of talking to the nurse counsellor. The counsellor was there to assess the woman's needs and desires for information, and her ability to process that information. Moreover, and perhaps of even greater importance, the counsellor gave each woman the chance to learn and analyse that information together with her. This was especially important following sessions with the doctor. The woman could then sit with the

counsellor and get further information and explanations about each of the facts she heard from the physician.

The Timing of Counselling

The timing of counselling was a major topic which was discussed with the women and the nurse counsellors. Both the nurses and the women mentioned that counselling was specifically needed at the initial time of confronting the diagnosis and hearing the word cancer. This was when emotional support and advice were particularly necessary. Being together with a professional nurse counsellor during these early minutes of shock, they said, had a positive effect on the later coping with the disease and its treatment. This can be seen as a time for intervention.

The time of decision-making concerning treatment was also mentioned as a critical point. As demonstrated in this work, some women will be involved in only one decision-making period with only one choice to be made (e.g. whether to join a clinical trial or not). Other women may face several such periods when choices have to be made at different times (e.g. a choice concerning the surgical procedure followed by a choice about the method of breast reconstruction, if mastectomy was performed). The time of decision-making can, therefore, be limited to one instance, or to several episodes being separated by a number of days or even weeks. Nurse counselling, as a form of helping women through the times of decision-making, was emphasised by the respondents to have a particular value.

As more and more counsellors are being employed in breast care, there is a growing need for understanding the importance of the timing of counselling. Counselling is a specific form of intervention, and therefore the timing of that intervention is crucial in order to achieve the desired result. Nurses who accompany the women through the entire breast cancer continuum have the possibility of timing this therapeutic relationship.

A most important point that was mentioned in this context was that some women may wish to be alone at these stages. They prefer to deal with the news by themselves. Sophie provided an extreme example of such a case.

She said that the only thing she wanted was to be by herself and quiet at this point. Even the comfort of her husband's company was not what she was looking for. Women like her may have to be approached in a different way, mainly giving them the reassurance that the counsellor is there to help them whenever they feel in the need of her help. Other women may be shy or frightened to look for the counsellor themselves, and the fact that the counsellor approaches them can make things much easier. As has been mentioned both by the women and the nurses, 'being there' and available at any time is an essential element of the counselling interaction.

Supporting Each Other - A Big Family

Several women in the interviews expressed the idea that counselling would be most reliable if the counsellor herself had experienced the disease. They said that women who 'have not been there', in the breast cancer path cannot **fully** understand those who experience the disease. A counsellor who 'has not been there' would probably not be able to provide the same emotional support and empathy as someone who knows from experience what it really is about. There is a special emotional bond between women who have experienced breast cancer that no one else can share. The nurse counsellors acknowledged that they could not know what it **really** means to be living with the disease, since they had never expereinced breast cancer themselves. Both the nurses and the women said, however, that it is of great benefit that the counsellor is also a woman. This provides the possibility of sharing feminine-related and even intimate matters which may be more difficult, or even impossible, to share with a male companion.

It is on the grounds of sharing experiences that many self-help support groups have been established. For some women these social meetings provide the only opportunity to receive emotional support. Furthermore, the women who participated in this study had all been treated in the same local specialised breast cancer unit and have been hospitalised together with women suffering the same disease. It was like a big family of women with breast cancer. This type of support was distinguished from professional support in the form of counselling. Saying this, it should be also mentioned that not all breast cancer patients enjoy the company of

fellow breast cancer patients. In fact, one of the 'Reach for Recovery' participants told of a fellow patient she knew who actually suffered from constant interaction with women who had breast cancer since they only talked about their disease, whereas she wanted to avoid thinking about it. In this respect the findings of the present work are limited. They are based on the reports of voluntary respondents, women who willingly established contact and were prepared to talk about their illness.

The Training of the Person Providing the Support

The current study underlines the need for more nurses trained in oncology counselling in breast cancer care. The importance of further training in the field was particularly emphasised by the nurse counsellors themselves. They all mentioned that they lacked adequate knowledge in applying various counselling techniques. From their point of view, further training and qualification in breast cancer counselling was strongly welcomed.

Specialised training in counselling is extremely important, especially in the oncological setting. As suggested by Roberts and Fallowfield (1990) it is wrong to assume that being kind and understanding and having a few years of experience of working with cancer patients is enough in order to become a successful counsellor. Additionally, having personally gone through the experience of breast cancer can also not serve as a prerequisite for providing appropriate counselling and support.

Counselling and communication skills are components in the curriculum of nursing education. In many cases, however, the teaching of counselling does not include specific reference to cancer care. This is underlined by the results of a study done by Wilkinson (1992) who demonstrated that nurses working in cancer care often do not manage to communicate well with their patients. She showed in her study that nurses tend to use more blocking communication patterns with their cancer patients than facilitating ones. As a result, open communication between nurses and patients was found to be inhibited. Wilkinson (1992) further argued that communication should not be confused with counselling. Counselling in

general, and in breast cancer care in particular, requires specific skills and training.

In the United Kingdom, important attempts have been made to establish the training for oncology counselling (e.g. Maguire et al., 1980a ; Maguire et al., 1880b ; Tait et al., 1980 ; Maguire and Faulkner, 1988 ; Tait, 1989). Cancer counselling in general addresses topics such as disability and mortality and the confrontation of living with a chronic life-threatening malignant disease. An important additional element in the specific training in breast cancer care is the concentration on decision-making and its consequent effect on body-image, sexual identity, and feelings of femininity. Marital relationship counselling, specialising in the unique problems of husbands of women treated for breast cancer, is also important in this context.

Studies evaluating the training in breast cancer care should be welcomed in nursing research. Through such an evaluation further development of the existing training programmes will be possible. Looking at the specific issues that need to be addressed within the training in the area, can also provide an important topic for further enquiry.

Applying the Nurse Counselling Role

At this stage of the discussion issues related to the practice of breast care nurse counselling will be explored. There is an attempt to challenge some patterns in the existing practice and to provide some further prospects for the development of this helping scheme. Arguments will be raised rather than answers given.

The findings of this study demonstrated the value of **nurse counselling**. The value of the **breast care nurse counsellor** as a specialist independent post, however, is still open for debate. Both the women and the counsellors themselves did not question the importance of and need for additional psychological and emotional support for women with breast cancer. This was found to be of great significance in every aspect of coping with the illness, and at many crucial points along the breast cancer

continuum. In relation to decision-making, nurse counselling was shown to have specific value of providing information, explanation and emotional support. The questions that are now being asked are **how** and by **whom** should counselling be practised.

In this work nurses who specialised as counsellors were interviewed. They were all physically removed from the ward and shared a common feature in their work which was that they met the women with breast cancer at their separate offices. In some cases the counsellors were also doing home visits according to the women's needs. This way of practicing specialised counselling has become increasingly common as an integral part of breast cancer care. I would argue that it is shifted away from primary nursing, from the patient's bedside, and from the original setting of the ward.

Furthermore, the development of such a specialised post may raise some problems which have to be further addressed on the management and institutional levels:

1. By having a specialist person who is dedicated to deal with the psychological and emotional needs of women, nurses at the ward may become less motivated to talk to the women and communicate with them on a therapeutic professional level. This situation may encourage nurses to shift responsibility concerning this most important aspect of care to the specialist counsellor. It will result in nurses being more oriented towards physical care, rather than to the care of the woman as a whole.

2. The nurses in this study stated that using the word 'counsellor' created a problem: "Women did not want to think they need counselling" and "I am not a qualified trained counsellor" are just two examples of their comments. This resulted in confusions over a consistent title of their job and over exact definitions to their work.

3. Each one of the nurses had a different understanding of what she was entitled to do and what her commitments in working with women with breast cancer were. As described in chapter Six, some of the nurses in this study were more engaged in hospital work, whereas others concentrated more on work in the community.

4. Because of the high demand of women for additional counselling and support on the one hand, and the limited number of specialist nurse counsellors on the other hand, the needs of the women were not always met in the context of this interaction. The counsellor being too busy and having too little time was a common remark mentioned by the women. The nurse counsellors, in a different way, commented on the large case-load of work which they had to deal with.

5. Most of the nurses in this study, who were positioned as specialist nurse counsellors, felt that they did not have enough qualification and training for their most demanding role. They felt incompetent and at times unable to meet the requirements of the women. They all stressed that additional training is therefore urgently needed.

6. This specialised way of practising counselling is based, in general, on women making the effort to approach the counsellor. It may create a situation where women who are more reserved in their nature or less initiative in their character may not get the opportunity for receiving the necessary support.

Bringing Counselling Into the Ward

All the above mentioned are problems that may be initiated when making breast care nurse counselling an institutionalised specialised post. It is further argued that bringing counselling into the ward as an integral part of primary nursing, will help to overcome many of these difficulties. Counselling as part of the every-day nursing care is the suggested practice. This will encourage nurses to receive further skills and training for dealing with women's emotional and psychological needs. It will create a possibility for women to more freely approach the nurse, and will solve some confusions over definitions related to this specialist counselling post.

It must be mentioned, however, that bringing counselling into the ward will put additional pressures on the nursing services in the oncology units. More nursing staff will be needed in order to meet the high demands that counselling may call for. More training in counselling, and

specifically training in breast care counselling, will have to be offered to nurses working at the ward. As suggested by Wilkinson (1993), counselling should not be used interchangeably with communication. Counselling, and especially counselling in cancer care, requires specific training and qualification. However, if counselling becomes an integral part of breast cancer care, the quality of care given can be expected to rise to a new level.

Saying all this does not suggest that nurse counselling as a specialist post should be abolished. It does, however imply that such a notion needs to be re-addressed and further examined. The question of how to incorporate counselling into basic nursing care in the ward should continue to be of concern. The idea of nurses visiting women at home, in their natural environment where they can feel in control, is a specific issue which deserves special attention. Practical answers to these problems are beyond the scope of this work, but should become the focus of further investigations.

The practice of breast care nurse counselling involves meeting women at a very sensitive point in their lives when they have to confront many issues such as mortality, sexuality and a new social reality. In the area of breast cancer care nurses will increasingly have to find ways of working in situations where women are making decisions about their bodies and their lives. Decision-making served as an entrance door for a better understanding of the experience of breast cancer as a whole, and consequently of the help that nurses can offer women at this point. In the final conclusion chapter the goal is to exit the breast cancer decision-making door and to examine some wider relevant issues that have emerged through the analysis and writing up of the data. Three areas will be examined in the following chapter when looking at decision-making in a social context, these are: the right for information, women and the health care system, and education in the area of sexuality and breast cancer.

Chapter XI:

WIDER PERSPECTIVES AND CONCLUSIONS

Decision-Making in a Social Context

The social values and beliefs which people are brought up with influence their behaviour and way of thinking. This is especially noticeable when dealing with, for example, health related decision-making situations. This study which examined such issues was limited to the Scottish culture. The findings demonstrated that in the area of breast cancer women were influenced by their upbringing and acquired social values. This held true for both the women with breast cancer and the nurse counsellors who cared for them. In the following sections I would like to conclude by drawing attention to three main wider topics which are relevant to this work and which are influenced by social circumstances. These topics are the Right for Information, Women and the Health Care System, and Education in the Area of Sexuality and Breast Cancer.

The Right for Information

Social and political circumstances influence people in their wish and demand for information and for involvement in various areas of decision-making. On the whole, the members of a society that believes in the freedom of expression and in the basic human right of being involved in decision-making, are likely to be more assertive and information-seeking people. Modern democracy is based on these values.

An example of a less open society is well illustrated by Solzhenitsyn (1988). On the cancer ward which he described, the philosophy of the staff was to withhold information about the illness and treatment from the patients. The patients themselves did not search for information in addition to the limited amount they were offered. This demonstrated the values these people grew up with under the communist regime of the Soviet Union, which emphasised that one should never ask too much. Solzhenitsyn (1988) by analysing his experiences in a cancer ward gave his interpretation and criticism of the Russian society of that time. The communist party (which was analogous to the medical staff in the cancer ward) deprived people of information, just as the cancer victims in the book were deprived of knowledge regarding their diagnosis, treatment, and prognosis. I believe that Solzhenitsyn was trying to say that the effects of

communism were growing in that society just as cancer grows inside the body. Writing the book was his way of condemning some basic values that characterised the Russian society of the time.

Contrary to the example discussed above, in our western world changes are taking place in protecting the rights of people for information which concerns their own lives. An example from the UK perspective is the recent introduction of the British 'Citizen Charter' which is based on these ideas and which in the area of health care initiated the development of the 'Patient's Charter' (Scottish Office, 1991). The 'Patient's Charter' focused on the right of people for information and involvement in health care decision-making. Being directed to the patient, it stated, that: "You are entitled, if you want, to accurate, relevant and understandable explanations of: what is wrong; what the implications are; what the treatment is likely to involve and if you wish, a second opinion" (p.6). Furthermore, the statement went on by saying that: "You are entitled to be involved so far as is practical in making decisions about your own care, and whether possible given choices" (p.6). The 'Patient's Charter' also made it explicit that people should have access to any relevant information which concerns their own health. There should be no withholding of information and every person is entitled to be an active member in the planning of his or her care.

These developments are aimed at engaging people to participate in a mature interaction of 'Mutual Participation of Shared Responsibility' (Schain, 1980) when confronting the health care system. Such a collaborative interaction, however, cannot be easily practised within some cultures and social values. It may be difficult for people who have been used for generations to a patriarchal system of health care, where the doctor is seen as the highest authority, to start exercising a more mutual type of interaction. Moreover, an increase in the ability of patients to share responsibilities concerning their treatment may depend on a general shift of attitude in a particular society. It is, therefore, closely related to the development in political and social issues. Concepts such as emancipation, empowerment and control are not acceptable within some social systems, especially when related to women and their confrontation with the medical world. In these societies, in particular, there is a need to educate

and encourage people to take a more active role in decisions which affect their own lives.

The issue of the effects of culture and social values on the attitudes of people concerning involvement in health care decision-making should be further investigated. In breast cancer care specifically, attention can be given to comparing women from different social backgrounds regarding the way they wish to exercise control in the planning of their care.

Women and the Health Care System

This study provided some insights into the problems women face when they have to make health care decisions in a system which has long been male dominated. In our patriarchal society, men are the ones who have power and control over the provision of health care. Women share this power, but on a minor scale. In the specific case of breast cancer, women will often confront a male doctor and are subjected to the male hierarchical domination of the system. It seems that women are almost happy to be in this position, and one can argue that they are doing very little to change it. As this study has shown, even when given the possibility of exercising power and control, women did not know what to do, and directed control back to the powerful male. Furthermore, the possibility of sharing control in treatment decision-making was given to the women by men - the consultants who were in charge of their care. It was not really a situation controlled by the women themselves.

It is argued here that without a long term change of values through education, one could not expect women to know how to deal with such an 'unfamiliar' situation of choice. At this point I would like to return to Freire's (1972) notion of the 'Pedagogy of the Oppressed'. In his book, Freire suggested that revolution, the emancipation of the oppressed, can be achieved only through education. Moreover, Freire pointed out that emancipation must come from **within** the oppressed. Only power that stems from the oppressed, he believed, will free both the oppressed and the oppressor from the oppressed situation. These arguments can be applied, amongst others, in the case of breast cancer and decision-making. It is the power, emancipation and control as practised by women

themselves that will enable them to deal with the new demands and challenges brought about by the disease.

In connection with the above argument another important issue must be raised. The majority of nurses are women and as such are also subjected to the male hierarchical domination of the health care system. They have to confront decision-making and exercise power, emancipation, and control on the personal as well as professional levels.

Furthermore, the daily encounter of nurses with women who are in a situation of having to make crucial life decisions and who have to face the health care system, may provoke in nurses stress and anxiety as to their own position as women in this world. In this work I have tried to show through my own experiences that being a woman and a nurse who is engaged in studying this sensitive area may initiate anxiety, even without being diagnosed with the disease. Common issues related to women emerged as basic elements of the experience with the illness.

On the more professional level in their every-day work, nurses also have to face the power distribution which characterises the health care system. It is not within the aim and scope of this work to examine the position of nurses in the health care team. It should be noted, however, that nurses in their daily encounters with their male colleagues have the possibility as women to exercise and demonstrate the emancipation and power that increasingly represent their profession.

Education in the Area of Sexuality and Breast Cancer

In some societies breast cancer as a specific health related problem is still very much a taboo. Women, as well as men, find the topic extremely sensitive and difficult for discussion. In Scotland, where this study was conducted, there is a more traditional and conservative social system and a discourse about related topics such as body-image, sexuality, and femininity is not encouraged. This results in women not being able to talk openly with their partners and intimate friends about their most inner concerns, and consequently in many psycho-sexual issues being swept under the carpet.

It is my belief that a change in such an attitude can only happen when dealt with at a very early age. In the previous section the importance of education was mentioned. Education about health care and sexuality in schools is a specific way of facilitating girls and boys to talk openly about their bodies, sexual experiences, and gain general knowledge about gender issues that may be of concern to them. Breast cancer and its consequences come clearly as an integral part of such education. This will enable young women and men to be better prepared for and knowledgeable in discussing such life-related topics. Moreover, especially in the case of breast cancer, it is argued that because of the high incidence of the disease, a large proportion of girls may have a mother, aunt, sister or grandmother suffering form the illness. As has been demonstrated in earlier studies (see Chapter 2 - section on the effect of the illness on the daughters) having a mother with breast cancer can effect the daughter's sexual and psychological well being. If these issues are discussed within formal education such problems may be somewhat minimised.

Education about health care and sexuality in a broad sense will not only foster the possibility for an open dialogue, but will provide the tools for women who have to confront the disease to be more knowledgeable, assertive and demanding of control. This is one step towards empowerment and emancipation. Such education is focused on boys as well as girls. By being more informed and open-minded, men will also be better able to support their women through the path of the disease. Moreover, in the case of breast cancer, fostering openess about such matters will enable the couple to go through the decision-making process together, and the experience of the illness as a whole. Involvement of men will facilitate a situation where nurses will accompany the women and their families all throughout the breast cancer continuum. It is best understood within the tradition of the holistic approach to care. Early education, therefore, can be seen as a means for change in health care away from the traditional patriarchal system.

The value of early education is an issue that needs to be further explored. In the area of breast cancer, it would be beneficial to find out whether women who were exposed to education about sexuality and health care would be more assertive in their attitude and would experience fewer

psychological problems related to the disease and its treatment, than women who were deprived of such education.

EPILOGUE

This thesis started with a poem of the Israeli poet Yona Wallach who died at an early age from breast cancer. In this poem she demonstrated an extreme choice of rejecting her illness and its treatments. At the other end are patients who decide to fully accept the disease and who were described by Siegel (1986) as exceptional patients. They teach their carers the secrets of how one can cope with a threatening illness like cancer.

> Exceptional patients manifest the will to live in its most potent form. They take charge of their lives even if they were never able to before, and they work hard to achieve health and peace of mind. They do not rely on doctors to take the initiative but rather use them as members of a team, demanding the utmost in technique, resourcefulness, concern, and open-mindedness. (p.3)

Siegel (1986) further argued that every person has the capability of becoming an exceptional patient when confronted with the disease. Each of the women in this study has been an exceptional patient and has provided a unique insight into her dealing with the diagnosis of breast cancer and the decisions about treatment. There is no average or common way of coping with such a situation in life. It is the search for one's Self-World, accompanied by qualified information and support, that is the best guide in the decision-making process. Women should not let themselves be subjected to the authority of the medical system, but rather explore and make use of its advantages while exercising the power of freedom of choice. This is especially true when decisions regarding their own lives are to be made.

The story of Jo Spence is an example of an exceptional woman who chose to use art as a method of coping with her cancer. Jo Spence, an educational photographer, was diagnosed as having breast cancer when she was in her forties. Spence decided to use photography in order to help her understand what she was going through. Unlike Yonna Wallach, she openly and overtly confronted her illness and its treatment. She refused to have her breast removed, which was the conventional treatment offered to her. Her way of dealing with the illness and treatment was to take photographs in order to memorise her experiences. One such example is a photograph

which she took in which she was topless, where on her affected breast she wrote in big black letters **'Property of Jo Spence'**. She referred to this process of self expression as Phototherapy, which she explained as: "...using photography to heal ourselves" (Spence, 1986, p.23). The message behind her photographs was a feminist one, of a woman who clearly and assertively wanted to keep power and control of her own body and fate. Jo Spence used photography as the means to express what many women may feel, but find hard to articulate. However, she also described her experiences of coping with cancer in writing. In one of her articles she wrote:

> ...although I still have active cancer, and my general health is not good, I feel more in control of my life than at any other time previously. This has come about because of the questions I have been forced to ask myself about my belief system, my lifestyle and my attitude to my mind and body. As a result I see myself neither as a 'heroine' or 'victim', but merely as a person in struggle, changing and adjusting daily, and trying to keep a state of equilibrium which will allow me to function optimally, at the same time as I strive to regain health. (Spence, 1986, p.20)

Empowering women to become exceptional patients when confronted with, for example, the diagnosis of breast cancer is the goal for nursing in the future. It will entail the creation of circumstances that will allow women to make decisions about treatment in an extreme situation when inner power and control are most needed. This is where Kendall's (1992) 'Emancipatory Nursing Actions' which were described earlier on in this thesis can come into practice. Kendall suggested that: "...the nurse in the clinical area is in an especially important position to challenge the prevailing ideologic perspectives by focusing on clinical interventions toward empowerment over oppressive situations" (p.9).

I would like to end with Siegel's (1986) sensitive and most perceptive observation that: "since cancer patients typically feel little control over their lives, to the point where their own cells are in revolt, the mere fact of making a choice can itself be a turning point" (p.129). Enabling and encouraging women to perceive the experience of breast cancer and the decision-making process as a positive turning point, a step forward in life, is a challenge and privilege for nursing as a caring discipline.

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APPENDICES

APPENDIX 1

Letter of Invitation to the Women

Dear

My name is Ilana Kadmon and I am a nurse. At the moment I am doing research at Edinburgh University, in the Department of Nursing Studies, the work is about breast cancer.

My interest relates to women's participation in the choice of their treatment for breast cancer. The women's views of the help and support they can get from a nurse at that point is also important.

I would be very glad to sit and chat with you for a while about these matters. Therefore, I would be grateful if we can meet, at a time and place most suitable for you. **The nature and content of our conversation will be kept private, and you can always withdraw if you wish.**

Please call me for further information and/or to arrange a meeting, at the university :

Ilana Kadmon
Nursing Research Unit, Dep. of Nursing Studies
University of Edinburgh
12 Buccleuch Place
Tel. (031) 650 8442

Looking forward to hearing from you,

Ilana Kadmon

APPENDIX 2

Letter of Invitation to Nurse Counsellors

Ilana Kadmon
Nursing Research Unit
Dept. of Nursing Studies
University of Edinburgh
12 Buccleuch Place
Edinburgh EH8 9JT
Tel: (031) 650 8442
or - (031) 667 8757 (home)

17th August 1993

Dear

My name is Ilana Kadmon and I am a nurse. At present I am engaged in a research project toward a Ph.D. degree at the Department of Nursing Studies, University of Edinburgh. My thesis is concerned with the psychosocial aspects of breast cancer, and more specifically, with the woman's decision-making regarding her treatment in the case of primary breast cancer, and the role of nurse counselling.

I am a member of the Scottish Breast Care Nursing Network, and that is where I got your name from. We may have even met in one of the previous study days. The reason I am writing to you now is because I understand that you are involved in counselling work with breast cancer patients, and I would be interested to sit and talk with you about some aspects of your work. Mainly, I would like to hear your views and ideas about the participation of women in the choice of their treatment. This may add an important contribution to my study.

I would be grateful, therefore, if we could meet at a time and place most comfortable for you. If this is fine with you, please contact me at one of the above telephone numbers, so we can make appropriate arrangements.

Looking very much forward to hearing from you, and thank you in advance,

Yours sincerely,

Ilana Kadmon

APPENDIX 3

Topics for Interviews with Women

* Information given about diagnosis and treatment: who? when? how?

* Presentation of treatment options.

* Advantages and disadvantages of options.

* Influencing factors in decision-making.

* People involved in decision-making process and social support.

* The experience of choosing a treatment.

* Counselling - views in general.

* Counselling - specific personal experience.

* Nursing counselling and support at the point of choosing a treatment for breast cancer.

APPENDIX 4

Two Transcrips of Interviews with Women

Interview (9) with SANDRA

S: Well, I visit my doctor maybe once a month or every six week, for a health check-up, he keeps checking my weight and general health, you know. So in one of the visits he suggested eh... how would I like to go for a mammogram? So I said 'right, I will go' I mean I like to go for smear tests and things, to see that I am fine. So I went to the place, I think at Gorgi - I can't remember the name...

IK: A screening centre?

S: Yes, it's a screening centre. And I had my mammogram and I thought everything is fine. A week later they asked me to go back, they were not sure about something, so I said 'fine'. So I went back and I had the mammogram and then I was sent to [the specialised hospital] for another check, and they did discover that I had a lump, they call it a nodule, and that I will have to come in so they remove it. So I said 'fine'. So they didn't waste much time and I was operated straight after. The mammogram was in March.

IK: So the mammogram was in March...?

S: At the end of March, and at the 8th of April was the operation. I think just a fortnight was between. And everything was fine. They did a wide local excision... they said they will take away some lymph glands and they had to sent it for a check... and then they gave me an option to go on to Tamoxifen...

IK: After the operation?

S: After the operation. Or to go to the Western and to have radiotherapy treatment, for five weeks, every day for ten minutes. Or... you could have the two treatments together, you could have the radiotherapy and take the Tamoxifen. Tamoxifen is for five years, one tablet every day. Or I could opt for no treatment what so ever.

IK: So they gave you a complete option? And it has nothing to do with the trials going on in the hospital at the time - they just gave you the three options: the option of going for Tamoxifen tablets, to go for radiotherapy for five weeks, or both, or nothing... so four options?

S: Four options. So I didn't know what to do really. I've heard so many different things about radiotherapy, and I didn't know of anybody who has been on Tamoxifen, and I thought 'Well, I don't just want to do nothing at all' 'cause if there will be a recurrence I might sit and blame myself 'if only I had decided to do something...'. So, I went to my doctor [G.P.] and I asked his advice on the matter. He was very helpful, and suggested I go on the tablets, the Tamoxifen for five years, and that was what I decided and he prescribed the tablets. So they gave me sort of middle strength, and I do take one every day, and I have no side effects. So that basically is it.

IK: OK...

S: Did I miss anything out? Have I not been precise enough?

IK: No, no, that's fine. Let's go backwards now, to the minute of the information giving, the first minute that you were given the information that you actually have a tumour, which was in [the specialised unit] probably?

S: Yes, she - I think a doctor, told me, in a room on my own of course, and I was rather shocked - you know, but I thought 'well, it happens to millions of people, I am not alone in this world with a tumour'.

IK: And you didn't know if it was a nurse or a doctor?

S: I think it was probably a doctor, I can't remember that person anyway... I did feel a wee bit shaken, and she said, you know 'this is probably not the news you have expected, did you?' and I said 'Not really, but if that is what it's to be then fair enough' so yes, I did get a bit of a fright but eventually I had thought myself lucky, insomuch as I had been caught with the tumour at an early stage.

IK: Now, where the options already presented to you at that stage?

S: No, not that I can remember.

IK: Concerning treatment? Was any treatment already discussed then?

S: Treatment was discussed at a later stage and I saw a radiologists after that, from the Western, they were very nice and they just said that I have to have the tumour removed and then go to the Western for the radiotherapy treatment, I had no option to that.

IK: So he told you what will happen?

S: Yes, he told me exactly what it will involve, and I said 'fair enough' and I have accepted it. But it was changed after I have been to the hospital, even before the op, the doctor said 'do you realize what you will have to

do afterwards?' and I said 'I will go to the Western for the radiotherapy', and he said 'well, that may not be necessary and it all depends on the results of the biopsy'

IK: And the results of the biopsy showed...

S: That I had a non-spreading type cancer.

IK: Ahha...

S: Yes. Nothing spread to the lymph nodes. So then they said 'we can give you these option?'

IK: Em... were there any options presented concerning the operation?

S: No.

IK: So it was a straight forward thing that you will have a lumpectomy?

S: Nothing concerning the operation was discussed, no. They did say years ago that if you have a lump they would take your breast off. I have a friend and that's what happened to her. But you see, there is such advanced technology now that they just take the lump away and they take sufficient round about to ensure it will not spread.

IK: Let's say hypothetically, let's say and think together, that you... perhaps your lump was a bit bigger, or whatever, let's say that you were given the option between mastectomy or lumpectomy, with a further treatment. Sometimes they tell the woman 'we don't know what is really medically better, and you can choose either to have a mastectomy or a lumpectomy', can you imagine what you would have chosen?

S: I am not sure, it is a very difficult question. I mean, if they came and told me I needed a mastectomy I would just go ahead with that, but if they could only take the lump away, I think that is better.

IK: Did you ever have the thought of mastectomy in the back of your mind?

S: Oh yes, I did have, very much so. But they said I was one of the fortunate ones, and probably a lumpectomy could be done.

IK: So you can imagine that you would prefer the lumpectomy if the options would have been given to you?

S: Yes I would prefer the lumpectomy.

IK: To preserve the breast?

S: I think so, yes.

IK: Now going back again to the decision-making concerning treatment, the options that you were given, can you recall the experience of that?

S: Well, I can say that it is a very hard decision to make, I didn't know what will be best, and nobody has seemed to be able to advice me, so I thought, you know... I did wait to see [the counsellor] the other day that I was told about the options, but she was so busy that I went away, but I don't know if she would have been able to tell me anyway, because they would leave the entire decision to you. So this is why I have found it difficult - to have someone to advice me... so my doctor thought it was a good idea.

IK: So you got advice from your doctor?

S: I got advice from my doctor, yes. But it is a very big decision, how do you know which is best? I could have had all my treatment over within five weeks, if I decided to go to the Western, which might have been better than taking the Tamoxifen for five years, but em... this is what I have done so... I hope I have made the right decision.

IK: You're not sure?...

S: So many people gave me so many different advices...

IK: Who did you involve in the decision-making, apart from the doctor?

S: Well, I asked my husband ' what should I do?' but he didn't really know, he said 'Well, that is really up to you, I couldn't advice you on that'... So, it was a very big decision... and I didn't know what to do. I knew that I didn't want to do nothing, I might have been alright, but how does that help people in a research if, you know, if I decided to do nothing? Like yourself. Would I have helped you in any way if I decided not to go...

IK: This is also a decision...

S: Did you have many people like me?

IK: Who have had to decide between treatments?

S: Yes, yes.

IK: Well, I am basically talking mostly to women that had decisions to make, now not all the decisions are decisions which are exactly the medical decisions you are talking about. Sometimes it might even be decisions like if someone had a mastectomy, whether to go for

reconstruction or not, and sometimes it's more... even a more extreme decision: whether to go for a mastectomy or a lumpectomy.

S: What would you have done in my situation?

IK: Obviously I can't say, it's very personal... I can only tell you that em... from the literature I know... but, let's look at it that way, if there was a clear cut knowledge that one treatment would have been better for you than the other, medically, you wouldn't have been given the choice. So if you were given the choice a) It means that they don't know really any significant difference between the treatments, and that's why the options have been given to you, and b) It's your right to be involved in that decision-making isn't it...?

S: That's right.

IK: So I can't tell you really what I would choose. But I think that the important thing is that you made the choice yourself, you decided... and... are you happy with that choice?

S: Yes, I am happy, I had no side effects... I don't know if the option for radiotherapy still will be open to me or what... but em... yes, I am happy with the decision.

IK: So that's the important thing, isn't it?

S: I have to go back in August for a check-up...

IK: Ahha...

S: Every three months I need a check-up... well, they were so busy so I got an appointment only for August.

IK: Now, what do you think in general about the idea of giving a woman the possibility to choose?

S: It is a fair idea but a very difficult one to make. I mean if I had been told 'you are going for radiotherapy' and that was it, which I was told at the beginning by Dr. R ... I mean I was quite resigned by the fact that that was what they were going to do, but then the options came I thought 'Oh, that's good, I might not have to go for the radiotherapy after all...'

IK: So you were happy to get the possibility to choose, although it was difficult?

S: Yes, yes, I was happy.

IK: So you wouldn't have preferred someone to tell you 'that's going to be your treatment'?

S: No, no. I think that I enjoyed the fact that they have opened options to me.

IK: O.K., let's go into the next sort of topic which will lead us forward, and that is really counselling. What do you think is counselling? What is your experience of counselling...?

S: You mean from the hospital? I think the counselling was excellent, absolutely excellent. I don't know if there is an awful lot of counselling they can give you, but I think they were great - they were there when you needed them to ask them any questions, and they were very good.

IK: Did you find yourself in the need for counselling?

S: I was a bit shocked at first, when I heard the news, I mean... it is really difficult and was particularly in need of counselling then.

IK: So counselling is important at the point of the initial news.

S: Yes. I mean it was quite a shock... but they do what they can for you.

IK: Concerning the decision-making, did you find any need for counselling then?

S: No, no, I thought that was entirely up to me, I was left on my own really - I didn't even know who to turn to for counselling, so this is why I thought I will go to my doctor, he probably could give me some idea... He was quite surprised too when he heard, you know, what I was told... but em.., yes, I think the advice was very good from the doctor. I mean, like with [the counsellor], I don't know if she would have been able to have told me anyway, she might have been able to have advised me but, you know, it was my decision, so there was nothing like she could say 'yes, I think you should go on to Tamoxifen' or 'I think you should go for the radiotherapy treatment'... But, it is a very hard decision... I mean I didn't want just to do nothing. I mean I might have been alright by not doing anything, but eh... they told me about the study, and if I can help in anybody's study - I am willing to.

IK: So you didn't talk to [the counsellor] at that point?

S: I didn't at that point - no. But I did wait to see her that day to get her advice, but I had already been in the hospital for a couple of hours or so and em... she was busy and I didn't stay.

IK: When did you feel you needed to talk to her?

S: Well, I felt I needed to see her that day, but I couldn't wait any longer, I think I maybe had enough of the hospital... but you know, when you are waiting waiting and waiting... My husband was with me and he said we should wait to get in, but the lady before me obviously needed more counselling than me. [The counsellor] phoned me of course, she knew I had been waiting, so she phoned, and she has been able to advise me on the telephone - so it was very nice of her.

IK: And what did she say on the telephone?

S: I think she said that if I wasn't sure what to do I should go and see her. But I thought 'She wouldn't be able to advise me any better than my doctor, so I will go and see him'.

IK: So, if I understand correctly, and please tell me if I am wrong, in your experience with counselling there were two major points where you found the need to see someone, to talk to someone.

S: Yes, to speak, to talk, because it is a shock to your system really when you are told that, and to talk it over with someone is much better.

IK: So counselling is talking it over with someone?

S: Yes, sharing.

IK: So these two points were: one at the initial hearing of the word cancer, and the second one is really when you had to make decisions, am I right?

S: Yes...

IK: These were the points were you found yourself in the need...

S: Yes, I was a bit shocked when I was told the diagnosis, it felt rather... I was shaking really, and there wasn't somebody waiting for me when I came out either. The person, the friend that came with me she had to go, so... but I phoned my husband and asked him to come and collect me, because it was just close to his finishing time, and I told him on the way home in the car. But he is very quiet - he doesn't say very much. But these were the times when I could have done with somebody to talk it over with, a counsellor.

IK: What else do you think about counselling? What sort of other ideas do you maybe have?

S: I don't think there is an awful lot that I can tell you about it. I am not experienced enough in the medical world, so that you can ask the counsellor on the spur of the moment.

IK: So it's giving information - general knowledge that you might not have by not being in the medical field?

S: Yes, yes.

IK: Did you see other women, while being in hospital, and their experiences with counselling?

S: Not really, no, I didn't.

IK: So you were in the hospital for one day?

S: I came in on the Sunday, they did the operation on the Monday and I think I would have gone home on Tuesday, but I have been terribly sick after the operation, probably the anaesthetic, you know, so they decided to keep me another day...

IK: Another day of being spoiled... Maybe you can tell me a bit about the experience in the hospital?

S: I went in on Sunday, and the operation was the next day. I was last on the list... but I think it was a quarter to twelve, and they said to me 'alright...' , I was just terribly sick when I came out of the anaesthetic, but that happens to a lot of people...

IK: Now, one unique thing about [the breast unit] is obviously that it is a breast cancer specialist place, all patients there are suffering from breast diseases. Maybe you can tell me about meeting other women there? And... how did you feel being in this environment of...?

S: Well, em... all the women had the same thing as myself, some were even worse off than me, you know, having a mastectomy, but everyone was very cheerful and happy, you know, there is nobody that is going around with tears, everybody is so cheery. The staff were so nice, they were all at first names and... The nurses like to be called by their first name, and they are really very nice. I mean I was just sick that day, you know, I could hardly have a word with anyone...oh dear... but I got over that. So it wasn't traumatic anyway, everyone was very relaxed and nothing is rushed - nobody is in a hurry. They make you feel very at home, and I think it is a very nice hospital.

IK: Going a bit backwards, again to counselling, do you have any views or ideas about nursing and counselling?

S: I think it must be quite a hard thing for a nurse to be able to counsel as well, I mean... but eh... I didn't see [the counsellor] in the start, she was probably off on holiday, I saw another nurse and she was very nice as well, and very helpful in every way.

IK: For example?

S: Just very supportive, yes, supportive...

IK: Maybe looking again at the decision-making, do you remember yourself in the past taking decisions as important as this?

S: No, I don't think so. I think this was a very difficult one to make.

IK: The most difficult decision?

S: Yes. I had lots of decisions in my life to make, but that was a very difficult one. If they maybe just have given me two options, it might have been easier... but I had four.

IK: Because they told you you could also do nothing, did that make it more difficult?

S: Yes, it did. Because one or two people I have spoken to said, you know, 'oh, if it was me, I wouldn't do anything...', that was what they had thought, so it made my decision very hard.

IK: So you think, what might be difficult is having many options?

S: Yes, that's true, and then listening to people's opinion makes you think 'what do people in such a situation do?'

IK: How long did you have to make that decision?

S: About a week or so. After they have operated I had to go back and tell them what I wanted to do... about a week.

IK: For giving women the possibility to choose treatment, for example, what recommendations would you give, I mean for the staff who present the women with these possibilities?

S: I don't know how you can make it easier, I think it must be a hard job to do.

IK: To present the options?

S: You can't tell the women what to do, but you can talk with her about it... I could have finished the treatment in five weeks and not five years... but hopefully I trust I have done the right thing.

IK: Do you think that it's morally and ethically right to give women the options to decide if there is no clear-cut medical evidence,

S: Yes, I think it's a good idea to give options, but on the other hand you have to give advice, especially if there is no clear-cut evidence.

IK: But you know, about ten/twenty years ago, they wouldn't have done that.

S: They wouldn't have given any options, the breast would have just been removed and that was the end. Even my mom, they never gave any options to her, and that was about twenty years ago.

IK: So you think that is a good development?

S: Yes, it's very good.

IK: So how do you feel now?

S: I feel fine, I feel back to normal. I was a bit tired when I went back to work, but that was because I have been off for six weeks. I really feel fine now... I take the tablets at night, because it is more convenient - probably I would forget in the rush in the morning. And I would just like to say how excellent the hospital staff were in all aspects of my experiences throughout my stay. I cannot praise them enough for the marvellous support between staff and patients which exists, and hope they never close that Hospital.

Interview (10) with LYNN

L: I found the lump I had myself, at Easter this year. I went to the G.P. after waiting a couple of weeks, and then I was sent to the Infirmary which is a normal procedure. The first contact I had was with a doctor, and it wasn't the best that could have been, but this I must say, was an exception. It was a doctor that didn't introduce himself and put me at a distance. He went through an examination and didn't feel the lump where I thought the lump was. I felt unhappy about that, and I went through a mammogram. The second doctor, who was a consultant at [the specialised unit], already at the beginning very much making contact with you, reassuring and giving hope, and he found the lump exactly were I thought it was. The first doctor I talked to was a houseman, somebody perhaps not really trained, and it went on to the stage where I got the results of the needle test, and I had an exceptional long wait, which is acceptable, but it was again this doctor who called me and said: "The tumour is malignant", which was stunning. The first few words are stunning. But in my case, I was very upset , felt very alone, and he happened to be not the personality, perhaps because he was Asian and he had difficulty to talk and he left the room, and he didn't come back. Nobody came back. So I was left in this very small room in a very nice place with this word cancer. Not just breast cancer, I think cancer was what he comment on. I became almost hysterical, hyperventilating and sobbing and holding my knees. I tried to find some bell to push or something near, loosing control of myself really, anxious. At that time a nurse came in and called the doctor, and was hugging me, holding my knees, saying there is nothing to worry. In that case it happened to be not the right person giving me the most important news I ever heard in my life. And in this respect it was a really a very bad start for me copingwise, although generally I feel I am quite a good coper, and I also realized that that doctor couldn't be moved from that particular unit. Possibly he just is not able to communicate. I don't know how women in [the unit] are normally given the news, but I suspect that very positively and calmly.

IK: Can I just ask you when was it?

L: That was May of this year. So Mr. D [the consultant] then started to explain but you didn't hear it very clearly at that time, and that's when I met [the counsellor] who was called immediately. Everyone was trying to calm me down and get me back into proportion. And [the counsellor] took me along to her room and she turned me around. She is the one person that was able to very slowly put me back to shape. She gave me so much time and I think that this was when the news were really broken, and she gave me the possibility to go through absolutely everything, to make up my mind. She asked me who would I like to phone. I was divorced so I didn't have a husband to phone, my mother is seventy seven and a widow, you can't call her to come and help me, so she was very good and she called somebody at my work because I had to go to my work during

that day since I expected everything to be normal. So she managed to find me the person that I will need out of the building. I have got a thirteen years old son, I couldn't call him, and I was worried what to tell him. I think he was my first thought. I would probably want to say, I have nothing against single parents, but if you have a child on your own, and I have for nine years now, you have this person as your responsibility, and therefore my thoughts were what will happen to Richard. And not so much of myself, I really wasn't thinking about what is mastectomy, what lumpectomy was, it was really about my dependant and what will be with him. He doesn't see his father at all, so by whom will he be looked after? That was awful - what's going to happen to my son. That was really the worst thing.

IK: Yes... So what was the information actually given to you?

L: [the counsellor], she explained that I will be brought in for testing and that they are going to check the whole of your body, and then that there are cancer kind of surgeries, lumpectomy or mastectomy. No discussion then as to what I will need. She never mentioned that "I think this is the case for you" until all energy came back to me. And at [the unit] the three days were quite intensive, but all the patients are together and you find yourself in a self support group. Not an awful lot of information is given about the treatment really, but they did mention a few times that whatever decision will be made it will be made with the patient. That is why they asked you to bring somebody on Wednesday, that whatever information you are given you are not on your own, to ensure extra support from your husband or partner or whoever. It was on the Wednesday that I was told it was a very small lump, and that a lumpectomy will be done immediately. And after that there will be a decision as to whether chemotherapy or overectomy or radiotherapy. There was also a study going on at that time that meant that if I will be going to the study I will be picked randomly to one of the treatments.

IK: So you have made a decision to go to the study?

L: Yes, with no pressure, no pressure at all! I didn't even doubt it. They gave the impression that the treatments are equally successful. In my case, I wanted to be as helpful as possible and therefore the study seemed the right thing.

IK: So the study was whether to have radiotherapy or not?

L: Radiotherapy, chemotherapy or an overectomy.

IK: So the first decision was whether you want to go into the study and you have made it clear that you do?

L: That's right.

IK: Do you have any memories of that decision-making? Any doubts, difficulties, things that made you come to that decision?

L: I think I just generally wanted to be helpful... you want to help the people that are helping you. But I recognise that if they would have thought that I need one particular treatment, because if there were reasons for that and evidence for it, I would be given the treatment needed. So there was not any information to go on... so I had a small lump, early stage, no symptoms or anything, and the study was appropriate for me to go in to. So I think I decided on the spot to do that.

IK: So that was not too difficult?

L: No, not for me, no. But what happened then was that this study wasn't good for me - but you couldn't tell. And they said that I would have chemotherapy, that is what they came up with for me, which looking back now is a thing that actually makes you ill, the breast cancer treatment, apart from surgery, which doesn't really, it's quite straight forward surgery. Chemotherapy takes a lot out of you, and perhaps had I known a bit more how it would affect me, I wouldn't agree to have it. I was though given information and I could talk to anybody about it, but they can't tell how you react to chemotherapy, and it did take a lot out of me.

IK: So you were assigned to chemotherapy and you started the process straight away?

L: That's right.

IK: How often did you get the treatment?

L: Well, I started getting the treatment at 2-3 weeks after the surgery and I had six sessions, two and then went for radiotherapy which was specific to the area, and then the following final four after the radiotherapy was finishes. I was quite happy with that because I felt that the chemotherapy is systemic and therefore it's going to go all around your body and I felt good about that, I was more pleased than just having radiotherapy which is specific to that area. But the treatment itself took a lot out of me. I had one chemotherapy and then they waited for your blood counts. I had my blood checked after three weeks and then I had the second amount of chemotherapy. I got over that fine and then I started radiotherapy, feeling fine about the whole thing really. After two days of radiotherapy I thought the scar felt a bit sore, I felt a lump and I had mentioned it at visits, and the doctor suggested another needle test. After three days at the radiotherapy you see the consultant regularly every week, so I said I wasn't happy about the thing itself - it looked the same kind of lump. So, he did a needle test and he told me about four days later that it is a second tumour, which meant... no in that case it was a radiooncologist.

IK: Dr. R?

L: That's right, at the Western. And again, I wouldn't say it was the best way of hearing information. When I knew the needle test was positive it was very worrying for me. As soon as he said himself... malignant or whatever, I can't remember the statement, but he said it will mean a mastectomy, and I knew that - that seemed to be automatic - remove all the tissue , and he said I should go also for heavier chemotherapy. He said: "I am worried", and when a consultant says this it is transferred immediately to the patient. And I was quite devastated, I was more upset then, than I had been once I got over the first information of having cancer, it was upsetting to know about the spread, and that it was so quick. And what he said to me was that the chemotherapy had no effect, which meant there were cells in my body which have not reacted to those drugs. That was, I think, his concern - that it hasn't been stopped yet. And there were about to start radiotherapy which would really clean the breast tissue from tumour. So I was very lucky in that respect. Fortunately, I was with a patient who had been at [the unit] with me, waiting for me at the Western to hear, just a friend, someone who became a friend, and she stayed with me and suggested that we go to [the unit] to speak with [the counsellor]. Although there are very good nurses at the Western, you can't have, I feel, you can't have two people who can counsel you, you need one person at your...

IK: To build a relationship with?

L: Yes, that's right. So I went up to [the unit] as a mastectomy patient. I was awfully visibly upset and... the sister of the ward she was very very good, she made straight a connection: "We get the guns out now" and managed to convince me, I really felt very much encouraged, so that helped then. [the counsellor] wasn't at the hospital at that day, but the sisters there are very very equiped at coping with people's anxieties, and didn't, certainly didn't make lies of it, didn't give me the impression that everything is going to be O.K. In fact she said that it's now time to get your business you know, in hand when you're feeling well, which is quite an awful thing to hear, but she said that on the basis of a single parent, I found it very kind. So I went and got a permission for my son and the house and all these things that you have to do, and in a very short period of time, I very quickly phoned my lawyer and had everything, including legal guidance drawn out, a new will, my funeral arrangement - everything was done in just a week and I felt great. It's like saying "That is dealt with", the lawyer is a woman which helped a lot and that was a very practical thing to do. So that was a form of counselling then, and once I was back at [the unit], [the counsellor] was available at that time, I think I saw her straight when I came out of the discussion with Dr. R and the surgeon. It's an automatic chance to see [the counsellor] and that's when she talks about prosthesis, which she didn't have before.

IK: So they have decided on a mastectomy then?

L: Yes.

IK: And were there any further treatments needed after the mastectomy?

L: No. I had to continue the radiotherapy that I already went through. That's right, there was something else they decided which I suppose is a bit of a grey area here for me, but because I am so confident at [the unit] and Mr. D, and feel perfectly that I am treated, that I had no doubts at all that they are professional, experienced and have expertise and everything. It may be that the lumpectomy was a wrong decision because in this case perhaps I needed a mastectomy. What I don't remember is if there ever was, in the very first stages, if I thought a mastectomy was preferable for me. I shall never know how I would have felt. I think now... I'm glad I had a lumpectomy, because I had time to think what a mastectomy means. Some of the women were very very open and took out the prosthesis to show you the scar, and you're getting used to the mastectomy area and I wasn't scared. At the time I knew I have to have a mastectomy it really didn't scare me at all, or matter to me physically, you know, the appearance. I think I just wanted the cancer gone, so you know, it becomes less important. But I had time to prepare myself to what mastectomy will be like.

IK: So we are back at [the unit] at the point of mastectomy.

L: Mr. D explained exactly how the operation will be, what the excision will be like, and what the skin will look like afterwards. At that point he said about tissue expansion and I realized that can be done in some cases, but Mr. D explained that I couldn't have that.

IK: Did he say why?

L: Because I needed radiotherapy immediately afterwards, and it will destroy the tissue. But he did say that within a year I might like to consider plastic surgery and mentioned the names of... so if I wanted to have that done I could think about it. But the state of mind that I was then was that I am not at that stage yet of the cosmetic thing of my body, you know. I just wanted the bad cells to go. It just didn't matter, there wasn't any discussion about that. But what the doctor decided was that I would have my ovaries removed in time of the mastectomy, which goes back to my lack of knowledge, I don't know enough about cancer. Part of me wants to know and part of me doesn't. I knew that different cancers have different receptive conditions, or that some are receptive to hormones, and this one apparently was, I don't again remember having given that information at an earlier stage, but it may have been that the right decision be that, or not the right decision the preferable decision, whether I should have a mastectomy and an ovarectomy the first time. The gap was only two

months, and in my terms that was enough to, you know, I don't think, I can't let it think, that it's life threatening kind of gap, so I'm not worried about that, but that's what the decision was then. And, I know your questions are about how much I was involved. At that time I didn't have a choice, I think at that time everyone said to me: "This is what you need, and that is what will help and leave it to the consultants and their decisions."

IK: So you were quite happy with not being given too much choice?

L: Yes, I was. He gave me confidence that it has to be done: "You are going to have this and very quickly..." that is the other amazing thing, it has so much effect and I can't give enough credit for how quick he dealt with things. I was so often so worried and Mr. D when I was referred back, so quickly took his diary and he couldn't fit any more and he has actually written in his diary 'no more' under the patients, in a day were there were so many operations, but he fitted me in. I saw him fitting me in. I could see what he was doing, he said: "I am making room for you, I want you to be in next week", and I was, which was wonderful. The degree of urgency that you feel is almost shared by... it conferms that they are all taking you seriously, and that was good, that was really helpful. The difficulty is if you have a long gap I believe. I heard of a relative in England who found a lump and was told something, I think like six weeks before she would have the operation, and that six weeks was an agonizing wait and friends and neighbours who then know have the wait with you as well, you don't have the support... so, I feel how they managed to operate so quickly is a great benefit to the patient.

IK: Going back to the choice of treatment and the involvement of the woman... do you have any idea, now, in general, can you picture what sort of women will be more willing or even happy to have participation in the treatment choice? and will some women perhaps prefer not to? From your experience, what do you see as strengths and difficulties in that?

L: I think it's very difficult. The staff at the hospital haven't got time to get to know you personally quickly enough and that's where [the counsellor] perhaps comes in, she somehow seems to have an intuition. I think she was in a very short amount of time able to find out people's social lives and locate and take in information about, I don't mean intelligence, but their ability to understand, and by the way they talk and the way they cope with the immediate situation she probably is the best able to know, to judge how much that person can cope with the disease, which is quite a painful position to be. She may suggest that somebody can see you more or less or be a quick guide of to how much you can cope with the situation. Is that what you mean?

IK: Yes, yes...

L: I think it's hand in hand. Doctors have such a high level of academic capability but you very much can't expect them to be trained in personal skills as well, and psychology. They are all human themselves, but... I think that the first step has to be about the person, not about the illness. And in any meeting with any doctor, you know, "Hello, how are you.." or anything that is an opening to see you as you and not as an illness or complication...

IK: How do you see nursing in relation to counselling in that respect?

L: I suppose, it's again hand in hand. The G.P., sorry the surgeon, he can't spend a lot of time on the counselling side, so I think it's right that in all life threatening illness at all, that counselling should be available. In case of women that are at home and bring up children it's even more important because they are carrying responsibility for other human beings as well. But I see the essential part... I can see what hard work [the counsellor] does at [the unit]. She is in constant demand and all the open door policy as well, it's not only people being referred to consultation, but almost everyone should be contacted. She even gives you her home phone number which I felt was wonderful. I think that is taking to personal... that happen to be one of the cases about nursing. When I had the mastectomy I was in for about ten days and that meant my son had to stay with a friend, which was not easy for me to accept, that he will be away from his own home, but I had... I went through all the normal procedures of getting better and towards the end of those ten days, not my consultant but the House Doctor came round and said: "Such about today, tomorrow you can go home" but not in that tone... and I said "But there is nobody at home", now at that point I haven't even walked down the hallway and it's been short distances of walking to the toilet. I did nothing and I lay in my bed and did nothing energetic at all.

IK: That was what day after the operation?

L: That was six days after.

IK: Ahha, so you haven't been doing much?

L: No, no, you know just short distances walks to the toilet but not of any length at all, so that I found extremely hard. That was someone I didn't know who came around the ward on the round and doing her job but, you know, "You can go home tomorrow" and when I said: "There is nobody at home to look after me" I immediately thought: why not stay a few more days? I thought: how would I get a meal ready, The washing done, do anything like shopping? It was horrendous to think of going home and your child and look after yourself, and trying to get over this discomfort. And when I said that to her, she just said: "You just take some help". I looked at the nurse behind me and she was kind of shaking her head and said: "It's O.K., don't worry" and that's a terrible thing, I was so upset and

cried and cried and cried and everything went trumbling down. I sat in the shower room and looked if there were signs in my chest - I felt awful, everything seemed worse than ever had been before, and I felt miserable. What I did is asked to talk to one of the nurses whom I liked, who was on the ward the very first day I was admitted and who took my particulars, she was very good then. I liked her, I felt this was somebody nice and we talked, and I asked: "how does cancer start?" and she said: "there are many theories but everyone has cancer cells in their body and sometimes they just don't prevent themselves..." it was just a nice chat and we talked about Richard and I explained about my ex-husband that I didn't want him to know and that if there was any call he wasn't allowed to see me and all these important things which are difficult to handle. And she was good. So on that day I said to her: "Before you go off duty could I have a wee time to talk to you?" And she said: "Yes of course" but in the meantime I just couldn't keep up this upset, so another nurse saw me crying laying in my bed, and she came and asked what was wrong?... and when I said that I just can't face going home basically, she said: "There is no pressure, no need to go home, nobody is throwing you out". But what I found hard with the nurses was that I was upset again and a different nurse in a new shift came along again to me... it was doing the right job but I felt it so hard to talk to the girls... I wanted to talk though! The first nurse went off duty and came and asked: "What is it you wanted to say?" It was approaching a weekend and I felt from my knowledge that it was all quiet at a weekend, and that new patients didn't come in till Sunday evening, so I thought if they let me stay Friday and Saturday, two more days, I might be feeling better. And the nurse didn't question and said the right things and before she went off duty she gave me a slip of paper with her phone number and she said: "When you are away from here, don't worry, if ever you want to talk to me you phone me up". And that was just... I haven't phoned her and, you know, I may never phone her, but the fact was that she said here you are, you're not on your own... was wonderful.

IK: That's nice...

L: I thought that was wonderful. And that gave me the lift I needed. And then [the counsellor] came back from the Infirmary and she said: "Come along and let's talk", and we had a really good chat and she sat and was trying to find out what was worrying me about going home by asking the right questions... and told me not to worry about the mastectomy. That was an area I felt was a bit insensitive of the House Doctor, because the day she spoke to me I haven't even had the softies - as they call it - fitted. So I felt 'what is it I am going to go out of the ward with?' That's and important area...

IK: The practical matters?

L: That's right... yes, yes, what am I going to look like? What do the softies look like? I haven't had the time... I was a fairly well patient that everyone felt was fine, I was quite strong and fit and young but nobody has thought to say to me that: when you get to the ward, a few days before you go out we show you what there is to fit and we will keep you looking good. It had that kind of... but there were also lots of shift changes, you know, you never could be sure which nurse can do that for you. And that's a very important procedure - getting fitted, and everyone in the ward is going through the same. And when you actually are getting fitted: "Another half an hour or so we take you and fit you out", that was a big thing. You really go up to that... and I mean... I remember being quite excited about it, coming out with my T shirt on and walking to the main ward that I was in and saying: "How does it look?" and things you would never be doing, I talked to the cleaning ladies and I said: "Which is it, right or left?" and they were good because they work in the ward all the time.

IK: So they could understand the joke?

L: Yes, they just came over the top and... so that was a good thing that day and the girl that fitted me, she seemed to be proud in doing that... and she took me along to... and said: "Look, Mrs. W is looking good", and she made a wee joke there, they always make jokes, you know. I think the nurses actually enjoy this relationship, but for the woman it's very personal... going with your own body to somebody who says: "Well, we put a little bit more puffing here, and a wee bit more up there.." and then you walk out with the bit they fitted for you... yes, it's really quite a difficult thing to cope with... but to go back to [the counsellor]... when she found out that I was worried about going home we talked about the problems and so, and she got on the phone right on the spot to the Social Work Department and said: "I have got a young woman here who had three operations and chemotherapy and radiotherapy and she has a child at home and nobody to help, can we have some home help?" And I came home on a Monday and went and stayed with my friend for a few days, and Richard was there as well, we came home together on the Monday and the Social Work Department phoned that morning and said: "Can we come around this afternoon?" And a lovely lady came and I was very upset and so very emotional, but she came and she said: "Well, we will have two mornings a week, two hours each morning. That is four hours a week of help and there is more if you need it - we see how we get on", and that was wonderful. So for about five or six weeks I had this lady coming twice a week and cleaning up, the house was hardly untidy, but this was absolutely wonderful. Now that was counselling [the counsellor] gave me - orgenising practical help. And she took interest in Richard. She would refer to my son as Richard immediately, I think that is a great sign of a counsellor, the ability to personalise the situation. As it happened I just met a friend, a male in the March before this happened. Somebody I knew from twenty years ago, he got a promotion and moved away... and we have just remet and we have just build up the relationship again. So he

was thrown into the trauma of coping with his girlfriend, as it were, who had such a personal thing, and she knew about Martin and was able to talk about him and and find out if he did help me and how did I feel about this, and how did he feel about that, and it was very good that she was able to remember names and bring my life in, it wasn't just talking about me, it was trying to see the whole life. That was very helpful, that counselling. And again [the counsellor] told me that at any time I could pick up the phone and the ward sister as well, any time you are worried, to pick up the phone. And I had chemotherapy so any time you walk along just come in. That's something great about [the unit] - it's certainly an open door.

IK: And now you're feeling O.K.?

L: I'm going back to work this week after almost eight months off work which is a long time and, you know, you become very removed from your job and all this which is around it. It becomes quite a difficult thing to go back. But my school is wonderful and they are trying to give me the chance to go home during the day when I want, the first few weeks up to Christmas, not to stay the whole day. And then in January I should be able to go fully back.

IK: So you get a lot of support from them...

L: There is... fortunately. I work for an employer who is somebody who can help in that way. Some people have terrible worries about money or they are self employed or whatever. The financial side is always there.

IK: But you know that support is always a two way system. Support comes to whoever looks for support, whoever deserves it, whoever has the right attitude.

L: I suppose some people just hide away. I do understand what you're saying... I feel happy about [the unit] so I want to go, and when I find things which I read that even might be interesting to [the counsellor], I want to tell her because we are all in the same game as it were, and that's fine.

APPENDIX 5

Transcript of 'Reach for Recovery' Group Meeting

(ED - refers to the Head of the local 'Reach for Recovery' group who was present at the meeting)

IK - When we look at this cause of events of breast cancer, everyone has probably his story of finding a lump or whatever, but probably one of the most important things at the beginning is the information - the minute, I can imagine, one of the crucial beginning points is the minute of getting the information. Does anyone have any particularly sort of memories or something fundamentally that she can tell us and that might be of interest?

- All I can remember was that all was at the top of my head, I think some of the other women will agree, you just don't take it in at that time. Somebody after that... you're not believing really. I feel that after that you need somebody - some counselling, somebody like the counsellor eventually. But I don't think everybody has got a counsellor - you know, not every place has a M, who really brought you down to earth and let you through it step by step.

ED - Was there anyone told in a very bad way? You know... No names.

- No, I mean really it hits below the belt anyway, but in a way it wasn't... I knew it myself that I probably had it, but it wasn't the initial, like the discovering... it was after I had been to the staging, I mean feeling it inside... and instead of saying "Well, it may not be it..." he said "You've got cancer" and that was that. I mean you have breast cancer...

- So you were sitting there getting that?

- Well... you have that at the Royal and I had to go for extra X-rays after having the bone scan, so they could discover what was what in the skull. And when I went back this particular doctor just said "Well, I don't think it's anything else other than cancer". It wasn't very nice...

- I can agree with you there because... I felt he was very brutal because he said "It's OK - we can do a mastectomy here...", and there was a nurse, who was an elderly lady, and I wandered why she was there? Was she there to catch me if I faint? Or was she there just purely to be there between the doctor and the patient? Because if I had been that woman at that situation, my first reaction would be to comfort the patient because as you said, it totally... you don't realise - it never leads... you realise that it is important that you understand what's wrong with you. But personally I think he

could say "I'm very sorry, we have to think of it as a possibility..." but they don't lead it to you gently. They just tell it very brutal and then you're out of that door and that nurse just sat there, she never once said "Look, we will have a cup of tea, we go and sit down and we will discuss it". You're out that door...

- Oh, no, I got someone to follow me.

- Well I didn't, and I felt that was really bad, and I had no one with me, and I went out and it was a room full of patients all waiting to be seen... and you feel like crying or just... you have to go out and see all these women sitting there and just got to straight walk out and nobody says "Look, hang on, wait a minute - you sit down there and take this through it" - you're out that door and that's when I thought this is very very bad, and I have since spoken to my doctor and said "You know, this really is not at all how the news should be broken", but they continue to do that. Whether it was that they had female doctors, whether a man that would realise how difficult it is to a woman to accept the fact that she is having her breast removed, or two breast removed, I don't know. But they are very very brutal, and this was a relatively young man - about 40, really young man, but I feel that in his little life surely he has got a wife, and if not... surely he would go home to his wife or whoever, and actually the same man that said "Well, you've got cancer". Surely it would be better if he could lead up to it in a gentler manner and then go on - pass you on to somebody else like the counsellor, who is understanding, a kind person, she sits you down and you can have a one to one conversation with her but I think perhaps it hasn't happened with most of us. I think we all have been told in a rather brutal manner as you said. And I went home thinking "I have not got M.S., I don't have Polio, it's not my leg that is coming off, it's my breast". And that's how I kept myself going and it wasn't until home that I broke out. But, I kept on trying to be positive and say "Breast don't matter, I am not losing my eye sight, I've not got Multiple Sclerosis..." and that kept me going till I got home and then I broke down, but I just feel that everyone more or less had a similar experience. I know many people would say that they were told well, but reasonably well could be...

- Yes, it was a lady doctor that told me and understood me well, but as you say even then, being told well was not taking it in...

- Do you find you were told reasonably well?

- Yes.

ED - Alice, you have been at the Royal?

- I came back to the Unit and stayed there for a couple of days... I was there on a Monday, went for X-rays on a Tuesday. Sister T spoke to me when I

came back, she wasn't very sure if my breast would be taken off or just the tumour was getting removed. It was up to the doctor to tell her.

- And that was the first time you knew you had cancer?

- Yes.

- Did they actually say cancer?

- No, no.

- Did they say that there was doubt that it might be cancer?

- They said something about that. So on a Tuesday night my husband came round and I told him that they said I should come round on the Wednesday morning and that I need to be there at 9 O'clock. So we came round at the following morning, I was sitting on my bed and he came and said "I am awfully sorry but you have got cancer" that was again...

IK - Can anyone recall at that time of information giving anything concerning options? Giving a bit of power to you, something of that sort?

ED - Yes... then again I'm in a different situation, I'm not a [breast cancer Unit] patient. And... I can only say that I had the best possible treatment because I had been through a biopsy - and they didn't think it was anything serious - and I went back to have my stitches out and they said "We are terribly sorry but it's malignant...". And he sat 20 minutes with me in the middle of a busy clinic and I kept saying "Oh, I'm sorry, I must go, you're busy..." and he said "We'll sit here and we will talk about it". And at that point the only choice I was given was... and he said "Which would you prefer?" and I said I had no idea, and all I could say was "I leave it to you, whatever you suggest" which was giving me a choice, I chose to let him make the decision and not let me make the choice. And he said "if it was my wife I would..." and I said "Fine, I will go along with that", but I did actually get a certain amount of choice. And it was discussed and I was told what makes the choice, and that if I get the axillary clearance what might happen and what it would be like. So... I did get the options. But, having been given the choice - I can't get round on him and say "Right, I let you decide".

- I did have a choice eventually, from the same person like you, that was send round to eventually, because I asked him for his opinion. My choice was... they discovered that it was a hormonal growth and that I could have my ovaries removed, and that that would shrink the tumour, but someone else, Sister T, told me that I could have injections rather than having my ovaries removed, and that wasn't discussed with the doctor. That's when I got a second opinion and I asked Mr. C after that. And from then on I only listened to him.

IK - So Mr. C made the decision in the end?

- No, I'm like you, I mean I was given an option which he thought was the best, and the stage I was at to save an operation because he could really not know if I would respond, it saved an operation... and that was Mr. C deciding the treatment. I was like...

IK - So you were quite happy about that?

- Oh yes, I have got absolute praise... But it should never prevent from getting a second opinion.

IK - Well, going to look for a second opinion is in a way also a decision.

- But if his manner had been different, I probably would...

ED - There is no one here that I was able to contact who was in the situation of being given choice, there are people that I have met who were given choice and they said "Right, I don't want to be given this now, I want to go away". And one lady in particular took three weeks until she decided and she contacted me and she came to see me and she talked for hours and she read about it, and she did everything before she made a decision...

- Could I say just one thing that I think people often forget. I was told very kindly and it wasn't that much of a shock... and I had needle biopsy at the Unit, and a week later I was told that yes, it was cancer and it needed a mastectomy and radiotherapy. But, the bit that shocked me, the bit that worried me was that it was a diagnosis of cancer, it wasn't the fact that it meant a mastectomy, and maybe in a way I'm fortunate that I have done nursing myself and I have seen other women which have had mastectomy and my mother in law had a mastectomy, one of my cousins had a mastectomy and I have seen those people looking very well. So the thought of loosing the breast really was the least frightening to me and I reckon I am very lucky in that, it was the overall picture of general health and my future that I worried about and not whether I had one breast, two breast... but to my way of thinking the shock comes when you are told you have cancer, not necessarily that you need a mastectomy.

- Yes, I agree with that. I actually did have a choice, I was given a choice to have a lumpectomy or a mastectomy and I chose to have a mastectomy. I chose to have a mastectomy... I suppose my choice was a lumpectomy with radiotherapy or a mastectomy and no more treatments. And that was why my choice was done, I just wanted them to remove the cancer, I couldn't care less whether I had one breast or two. I still don't feel...

IK - It seems that from all the women here, it seems that your choice was very dramatic, a very big one because, I mean it's the most profound let's

say, a choice if whether to have an axillary clearance and radiotherapy is a very big choice, but the breast is still removed. But it seems that this choice was really on a big scale, I mean whether to have the breast removed or not or whether to go for radiotherapy or not, and so on... can you remember what influenced the decision to go for a mastectomy, apart from wanting to get rid of the cancer?

- Partly I just wanted to get over with, and it meant that the whole process will be over much quicker. To have radiotherapy meant that it will go on for a long time. The other thing was that my father has died of cancer and he had radiotherapy and it upseted my mother a great deal. At this point my mother had just had a heart attack and I come from a village which where if you go, I mean this is a false assumption, but the people in the village who don't know very much about cancer, when they heard about someone who had to go up to Edinburgh to have radiotherapy, they thought that this was something to be talked about... and my mother was one of the people who really thought that this was... I have known people in the village who had mastectomy and radiotherapy 30 years ago and they are fine but people forget all that, they just remember the ones who have radiotherapy and then they died. So I didn't want to upset my mother any more if I could help it, but I knew that if I said to her "I had the operation but I don't need any radiotherapy" she would be less troubled. And... I was quite happy, I was doing it for me as well, and if I had... I was quite ready to have radiotherapy if it was necessary, I wasn't refusing it. You know all those things were in my mind.

ED - Tricia, what was your experience when you were actually given the diagnosis, were you been given any choices concerning the treatment or been told in any bad way?

- No... The plastic surgery, the plastic surgeon knew that I did a lot of swimming so he said "Bring in your swim-suit and I see what I can do" but it was a quite low cut... it's just literally a line across, and I am delighted that I don't have... I don't have to take out my top, put on my dressing gown... it is essential for me, but I appreciate not everybody would like to go through a surgery again. I have gone through a mastectomy, I had the radiotherapy, I had the chemotherapy, I have gone through a reconstruction... it's an on-going thing, and it's just something you have got to learn to live with, but certainly it was right for me. I think it's great that they can do that for people who want it.

- They give you a choice on that.

ED - Yes, I sometimes worry about whether some people feel they are agreeing to have all that done when they are not really wanting it. I did see one lady that... it was a day before her operation and she was a elderly lady and she was to have a reconstruction, and she said to me "I don't know why I am having this? I don't really want it" she said "I don't mind the

mastectomy" and I realized that it didn't do her any good, she said "I don't know why I am having all that done, I didn't like to say no". I said "Tell them, they won't mind" and she said "Well, I am the first on the list tomorrow morning" and I said "It doesn't matter, it's not being done yet, you can tell them" so I went and spoke to the counsellor and told her that she never liked to say no, you know, they went on to say "You have got to have a mastectomy but we can do all this" and she thought she had to agree with it all. And she really didn't want it all, she didn't see why she needed all this done. It didn't matter to her - she never wore a bathing costume and she never did any sun bathing and... when she phoned me shortly after she got home and she said she has just talked to her doctor and said how fortunate she has been that I had just happened to be coming on that day, because I spoke to the counsellor who has then spoke to the doctor and then they had discussed it again with her and she didn't have to go through the operation, and she has been quite happy about that.

IK - Maybe, maybe... when I look at the list of preconceptions, and I never thought about it, maybe that is another sort of thing that you have... It is appropriate to want a reconstruction... 'she will want her breast back', and maybe it's not so true and not all women apparently...

- I think they sort of not like to tell you the fact that you have got to have the mastectomy and they want to be able to say something positive.

- We started by talking about people having choices. The first thing after Ilana has opened up was Jean saying that it is a shock, that you are not taking it in, and everyone here, everyone agreed. Therefore if you are in the position of being given choices at the same time that you are given the news that... some feel inefficient to make the choice. Can you really decide that this is what I want?

IK - And maybe that is one of the reasons for giving the power to someone else?

ED - Yes, you do, but then it's... "All right..." but then there are other decisions that can't... and maybe your preconceptions as you say mean "Oh this is what the patient will be wanting, we have discussed it with her..." and the fact that this patient is sitting looking... doesn't really come into it, "we have have discussed it with her and she said she..." but did she really?...

IK - So we have come across... another thing very important that came up that choice, or giving the choice and being able to participate in the decision-making is very much related to the time: to when, it has strong connection to when. Maybe at one time it is appropriate and at other times it's not... so that I think is very important. Now coming from that, I think the next topic I would like to, the other idea of interest to me is counselling because it seems to be coming up from what we have

discussed and... First of all, does anyone have ideas about generally counselling, his experience with counselling, what is counselling, whether it's needed, whether it's not needed? I mean, this is really very much my interest. I think one of the ideas is very important to understand: giving choice is lovely, but it has to be related to counselling and information. In a way it's even unethical, one can say, to give choice without this appropriate side support. How can we give choice without supporting? But what is this support, what is this counselling? We all heard about the counsellor... but what is this this counselling? Does everyone need it? Why do we think that every woman needs counselling? Maybe some women don't?

- I am going to tell you that E came to see me a few days after I had my mastectomy and I was out, I didn't have the operation at the specialist Unit - I went elsewhere, and I was asked if I wanted this woman to visit me and I said "Well, why not" you know, but boy, I was glad to see her and she let me weep... I have a sister and a mother and I didn't want that they will be upset, you know, you want to put a brave face on it. You want to tell all your friends and family that it's all going fine and that you are not afraid, but you are, and you've got to be able to tell somebody. I think I was so fortunate. I think everyone wants to protect his family, like you protected your mother. It really does help if there is somebody who you can ask all sort of silly questions to maybe... you know...

ED - I hadn't been told before about reconstruction, and the person that told me was the doctor who did the mastectomy, and he sat on my bed and very kindly told me "It's not the end of the world - there is reconstruction", and nobody has thought to tell me about this or thought to tell me about... I thought "no one at all from the time that I went into the hospital to have it done has spoke to me..." and he was so kind and understanding and asked if I mind if he talked to my husband as well as myself, because it's like everything else, you are getting all this information but you are not sure that you can remember it and relate it all back, so he very kindly sat about 20 minutes with both of us and he was absolutely super, but the nursing staff - I was at the Royal, so I was the only one having a mastectomy, people having gall bladders and all sorts of other things, so you are only another patient and there was no one that could say "Here's a booklet" and it wasn't until he explained to me about... that I could have reconstruction if I wish, and then it wasn't until I actually got a prostheses... and this is another two months because I had twenty doses of chemotherapy, and it wasn't after I was fitted with a prostheses that I could get some information... and I found him very kind and very helpful. The nursing sisters and staff didn't know how to approach a mastectomy patient, didn't know what to say to you and how to go about...

IK - Is it connected to the fact that in the Royal it is a general surgical ward?

ED - Oh yes, you are just another patient in that bed and it so happened that I was in a good situation and it didn't worry me too much. And I had my twins at that time - they were eight years old, and my son was ten, and I couldn't tell them why and how serious it is, it wasn't just putting a brave face on, because I really felt as you have said it "Well, I have not got Multiple Sclerosis, I'm not going to die - I have lots of living to do" and that was my own personal feeling, but I do get on my own, I certainly didn't get any professional help, and my husband was up to... he thought he might have three young children to bring up, and nobody thought of talking to my husband. It was left to me to say "Don't worry, don't worry, I'm OK" and a few weeks after I went back to work again... the thing is that it's all very well if you feel your surgeon has given you the support, like my surgeon has given me the support at that point, but there is nothing like counselling. I mean a good surgeon, all right he can break the news well, and when you go for a check-up can support you, you can feel that you can contact him if there is any particular medical problem, but you need a lot more than that, because I was in the Royal and I had no support and nobody has spoken to me and no one... apart from the consultant again at the beginning speaking with my husband, but as I came out there was no one... I only knew people who died of breast cancer, not anybody, not one who has survived. And that is why I thought "if I have got to live then I cannot let this go on" we have got to get some support going and get people to go and see others and...

IK - Can I... can anyone remember a really profoundly good professional support, really something that affected her so much, and on the other hand, can someone remember that she was like maybe forced into a counselling session. I think that might be the situation as well, some people might, I am really questioning this, we all the time say counselling... every woman has to be seen by a counsellor - is it really so? Maybe some women were forced into the room with the counsellor to talk about things they didn't want or it wasn't appropriate or they didn't find they are going to get help from that person: The only support they can get is from their husband or their daughter or their best friend or whatever... so can anyone recall on this?

- I would say I think the husband should be brought in and become a part of it and be considered actually, but as time goes on you begin to meet more and more people and the husbands are the ones that don't meet them. They don't have anyone else, they are talking about forming a group, I think the husband... men are not good at getting together.

- But has anyone ever done really anything yet to make them...

ED - Yes... about four years ago I helped getting started a group in Fife and they met, again once a month, like ourselves and quite a number of the husbands have brought their wives and came back to collect them by car. And one of the husbands, his wife had a mastectomy, and he was there

every week, and he would meet people and while they were waiting outside for their wives to finish the meeting, they got chatting, and they have actually started a group at Fife on counselling, and it's going very well indeed. But, but saying that you are dealing with a smaller community, and this is the problem in keeping this group going, you're dealing with the Unit patients and these patients can be anywhere in Lothian, we can get someone from... It's time to get a smaller community again...

- If you come from the specialist Unit system, which I have, I personally don't know anyone who was there who they said "no he doesn't need counselling". You weren't forced into it but it's there and I know I gained from it. I don't have this experience in the Royal but I have got a number of friends that have, but again came to the Unit for reconstruction and then became a part of that. I definitely have come through that system and it's completely in my eyes... yes, I think you do need counselling. That is my view of that.

ED - Well I remember another experience of the other way round at another hospital. I got a phone call one day saying "would I come in and bring a 'softie' for that patient who had just had a mastectomy", but they said "She doesn't want any counselling". And I mean we don't call ourselves counsellors, we are not counsellors, we are volunteers, but she called us counsellors. And they kept on saying "But she doesn't want counselling", I said "Quite alright there is no need for her to have counselling, that's OK", so I went to the hospital, and that day I thought "Will I take it in to her or will I just leave it?"... and I said "no, I don't like the idea of just leaving it, I will take it in to her". So I saw the sister and I said "Well I brought it and can I take it" so she said "yes, yes come along". I went in, I opened the door and she looked up at me and she said... and she just burst into tears... and I sat there for a long while and I since spoke to that lady for many many hours, I also have seen her again and she says "I don't understand, I was so determined I could do this, I could cope with this, I could manage..." she obviously, from what I saw about her family and so on, I think she really ruined them all with her mind and everybody was expected to cope but she needed it. She said "When I looked at you, there is something about you, that I thought I should forget this coping mechanism that came up and I can let go". So I think it should be offered and let the patient decide whether she wants it.

IK - I must say I had a similar experience. Well, I'm approaching women at the Unit, they are giving them letters to invite them to contact me, but I don't want to contact any woman without her 100% willingness, so they are being given a letter and if this woman is willing she is contacting me. One woman phoned me and she said "I'm not really sure why I have called you, I think it is because of the counsellor, because she gave me the letter, and I'm not really sure why I called you and I'm not really sure if I want you to come and talk with me, but... but... but..." and she went on. So

I said "would you like us to meet then?" and she said "Maybe". To make the story short, I went there and she opened the door and she said "I'm not really sure if I want you to be here?" and you can imagine what I felt, but that was irrelevant at that moment. And I went in and talked with her about many other things, told her a bit about myself and so on... and at the end I was there for almost three hours and she was probably the best... it was a special sort of interaction, I think for both sides, and it's this rejection that sometimes mean "I really would like to talk, I need the talking", Sometimes... anyway, my next, and really my main interest is, if we sort of decided that counselling should be offered and counselling is a valuable thing, whatever it is again, what about nursing? What place has nursing in counselling? I mean, Do you think nurses are in a good position for counselling, what experience did you have with 'pure' nursing in relation to counselling, or maybe someone else should do the counselling? Maybe someone would argue "no, I don't think nurses are the ones to counsel me, nurses should change my bandage..."?

- About counselling... I have only been at the Unit, at the moment I am still having chemotherapy after the mastectomy, another two chemotherapies to have. Well, I really only had an experience through there and I can't really praise the place enough, as well as the counsellor and the nurses, they didn't force anything on me, they just wanted to help the patient, counselling to help you...

- You're coming up with the word cancer, breast cancer and you said exactly how I feel about that. Everything about mastectomy and breast cancer... loosing a breast or loosing two breasts surely wasn't the trauma, cancer was. and I mean, I literally have just finished the whole process, but yesterday, I mean the consultant said "Good bye! Think back two years..." and I can see it. And that's what I was fighting, not the... I really really don't think it's the mastectomy... for me it's not. But I think the counselling I had for cancer was more important than anything else... and like you I wanted to... you are so naive at the beginning because you learn more as you go along.

- As you have said, You rather have it all the way, I was given the options if I wanted... or chemotherapy treatments, and they get worse when you get into it. I said that I will have it just in case and I think you would rather put yourself to that, because you thought if anything, if it came back, you should have had that... and it's just that you are so suspicious and you want to get totally rid of it you will go extra treatment, unnecessarily perhaps, but you would do it, just to say "This is the treatment - you have done your bit, the doctors have done their bit" and hopefully that will be the end to it. as you say, it's cancer that you want to get rid of.

- As I say the thing that kept me going was "I don't have any other problems... I can cope with loosing a breast but could I cope so well with loosing a leg? or something like that".

ED - You said in your assumptions that, or preconceptions that doctors seem to think that women will automatically want a reconstruction, and this is a thing discussed throughout the world, not just in Britain and the assumption is that if you say to the person "sorry, you have breast cancer you need to have a mastectomy, but we can do a reconstruction..." and that that's what women all want. Now... I'm sure some of you heard about a study in Newcastle about three years ago, they did a research in Newcastle, I cannot point to figures of how many patients who had a choice because there wasn't medically, there wasn't evidence for them that they should have one op rather than the other and it was mastectomy or lumpectomy and they were given a free choice and the vast majority chose mastectomy. They were really given a lot of information about what the treatment would be like, what they would look like if they had a mastectomy, and what they would look like if they had lumpectomy and they were given as much information as possible. They were shocked, they couldn't believe the results... and they asked them again a year later if they were again given a choice and I think there was one from each group - one from the mastectomy group and one from the lumpectomy group who regreted the choice , but the general rule was that people were happy with the choice that they have made.

IK - But also the astonishing thing was that they found that many young women... and we often think that a young woman, she would definitely want to preserve her breast, and many young women chose mastectomy. Probably not wanting to go through the radiotherapy and all the reasons that you have mentioned...

- And younger women have younger children as well and they think about home...

IK - And radiotherapy is a long process.

ED - It's very difficult to have preconceptions on anything concerning breast cancer, because every single person is an individual and you cannot decide, and even going by how a person copes with the... you always come back to this how people have coped with all stresses in their lives and how that person will cope with cancer. There is no connection what so ever, I mean how a person copes with everything to the actual... That woman that I have told you about before... she has gone through all this but when it came to this she desperately needed help. So I mean you cannot preconceive how a person is going to react and I think one of the dangers is, and I have been speaking to general surgeons about my work, and they often ask if I think that if a patient is at a certain age she will want this treatment the younger person will want reconstruction or conservation, and I think it's totally wrong, you cannot... In fact there is one area in Scotland where if a person is seventy or over then you get no surgery.

- That's interesting you mentioning that because my mother in law was eighty one yesterday and she had a second mastectomy. she had a first mastectomy twenty years ago when she was sixty, for twenty years on, you know how you go back, and she went back for twenty years and then they discovered a lump at her second breast but they thought that for her age it was better to have a mastectomy because it saved her to have perhaps a lumpectomy and then also to go through radiotherapy, and they thought that for her age to be up and down, up and down to the hospital it would be far too much, instead of being there for five days and that's it. And at that time my husband was at university so he could take her backwards and forwards, and that wouldn't have been a problem but it would have still been too much for her probably... so she was given exactly the opposite of what you were saying, rather than considering the Tamoxifen even, they took the breast off and that would prevent it "no more surgery, no more anything..."

ED - I have met many patients over seventy , a good deal over seventy, and they are so active after the mastectomy - they're golfing they're walking or swimming... it is terrible to think that they obviously say "well if one is over seventy we will not consider a mastectomy". And that, I mean, is in Scotland.

IK - I think, as for me, a very important thing for nurses to give support is to... to really deal with the question themselves and to know what are their thoughts and their feelings towards all this, and not... to be very clear about how they feel about themselves and about... even about their breasts you know, and things like that. It is really important to give this support, but sure, we are sometimes faced with the situation were we are lost, were we don't have this support, and yes...

ED - I think there is a lot of improvement in that because even in the time that I've been doing this work, I would say in the last five years, I have done a lot of in-service training in hospitals, different hospitals. The oncology study day at the university... all hospitals do training, that speaking, the last one I did at M was sisters and district nurses they go out to see the patient, to counsel patients, and I spoke to them and after they said "You know, that has helped us to understand, to hear it from the patient", but in the last years they are listening to what you are saying, but all right, you may come forward individually to tell them, but from your experiences that I see it I pass on in that way... and there are a lot others like myself that do that work, and they are nurses... but the nurses are beginning to get training to cope with what the patient is experiencing.

IK - Many times when there is discommunication, many times it's connected to the threat of the staff member, it might be the surgeon, it might be the nurse, but many times what we interpret as patients as discommunication as something bad you know, we were not treated well enough, many times the reason for that is this threat and inability to

handle, inability to cope. I was told about a patient who was told in a terrible manner her diagnosis by a doctor who was very young, very untrained and he simply could not face it and left the room, you know, and left her alone and then the story goes to her, how did she feel being left alone there...?

- I think the nurses are a very important bridge between the doctors and patients, they may even understand a lot more than we do. We see things from the patient's point of view, but I think you need both types of counselling if you call it that, both what we can offer because we have had the experience and what the nurses can offer, something rather different, but they are a very good bridge between the doctors, who don't have enough time, and the patient.

IK - So we have listened to actually, we have listened to two things the fact that nursing has time, and perhaps nursing by its meaning has a time set for that, and the second thing is that most nurses are females...

- But this is how it's happening at the beginning, people find the lump and go to the G.P. and the G.P. says "away you go", and it's happening and I don't think it is something that will stop, you think things are really... people's approach to it is not what it should be, people don't know what they are talking about.

- My mastectomy was a year ago today, and for the last many months actually people have said to me "Oh, you have been so good about it, aren't you wonderful?" this meant that all was behind me, that's it - end of story. You are up and doing and you are feeling well you are back to your own self you get your energy back again and all the rest is over the radiotherapy ect...

IK - And I can imagine that that's when you feel very much alone sometimes...

- I am alright now but, you know, about once or twice I thought to myself that people don't know what I am feeling, that I might not see much of the future, you know, nobody knows you're thinking...

- Which goes back to counselling. In our cases there was a whole lot of counselling that they gave us...

- That's right.

- People have forgotten, you're looking at this permanent reminder, but somewhere above the line... It is important we are all together.

- Also I think that the clinic mostly it's a very friendly place, although you know a lot of people there feel bad, there are a lot of people that you know and you ask about so and so and asked how you are getting on and...

- I have a friend that very recently had a mastectomy at the unit, and she founds this sort of togetherness and the thing of breast cancer too much, and she used to go and lock herself at the bathroom, she didn't want everybody else...

- Yes, you sit in company you are talking about it and you have all different problems and you could think "Oh well, I am going to get this..."

- Can I come in here and just say I sometimes find it all ridiculous. I don't know if I am different but I really don't... I do have a young family, I do have a part time job and the last thing I think about is the fact that I had cancer. You know, I am fine, I am not frightened to talk about it and would like to give support if necessary, but you pick up your life again you go through this, I have gone through it all myself...

ED - Well, you going on with your life is what we want, that is what we want to see. All we are trying to get is this support is a core of women who would be willing far going on with their lives. I mean I was back to work... and you go on with your life but you are there to help the people at the early stages when you had no counselling, but you would be there or someone to help those at that stage. I want other people to lead there lives and as soon as possible to forget about it.

- But do you find it that when you go to these patients, do you find that they do have difficulty in accepting that they can't go back to what they had before?

ED - No, you find in my experience, I mean I am many years in the thing, I have only had one patient who had said "Oh, you know, I can't cope" and I said "Come on, you know you will fight it and you will get over it", "But I am not a fighter, I am just not that type of person and..." you have to keep encouraging and then when I phoned her up, she was a Unit patient, and then when I phoned her up to see how she was doing you get the answer "Hello" (cheerfully) and then I said "Hello, it's E" "Oh hello Evelyn" (sad tone changes). But that is the only, one but the vast majority you find that they will get over it and they will make the most of every minute that they have got. OK it's hard, there is no question about it, I think for many of you, and you are included, that comes a day when something happens and you say "Oh God..." you know, you get a pain or something and the immediate, the first thing that comes to mind that... it's natural, I mean surely if you had something, an experience like that that it is worrying at some point.

- I try always to get on with my life and work, but I see, I know what you mean... If I talk about it at all it's just to make people understand it, you know, after going through all that. I know I am not everybody...

ED - As I have said, I was back at work after three weeks, the thing that you have to be careful about is not to make people feel that everything is O.K.

- That is the case for me, I can appreciate it's not the case for others.

ED - I still think it is a bad to say to people "Oh, look at me, I was back at work in three weeks..."

- Aha, but that is me, that's me, that's not other patients or everyone.

ED - But if you are speaking to a patient you have to be careful not to say that because you could make them think "She went back to work at three weeks and look at me..."

- I think what people should realize is that you are not really thinking clearly for a while, I mean you are hypersensitive to everything that is said to you, you read other meanings into little... I remember being... it was said to me when I went down to radiotherapy, it was said to me "yes, it is a very difficult thing, you have a serious illness diagnosed". And I came away thinking... I thought I had a real serious illness... it was just somebody saying a little phrase like serious illness, life threatening illness, and it's stayed in me for weeks, you know, just a little thing... somebody who lightened something that worried you. Maybe a little more training for some of the nurses in counselling... just a little kinder...

- It takes time to get used to the idea and you got to be given the chance to to come to terms with things yourself, and whether it has to do with counselling or no counselling, no one can really do it for you.

- At the end of the day it's you, and you are on your own.

- people have no idea also what counselling is all about.

APPENDIX 6

Topics for Interviews with Nurse Counsellors

* A general description of the medical practice of breast cancer in the specific setting, including medical trials which are in progress.

* Information given to women about diagnosis and treatment options: by whom, when and how?

* Policy employed at the institution concerning giving women the possibility to participate in the decision-making regarding their treatment. What choices are given to the women?

* What form of emotional support is provided for women diagnoses with and treated for breast cancer?

* The counsellor's experience with women who are going through a decision-making process. Who are the women who take a more active role in the decision-making process, compared to others who wish to leave the decision with the doctors?

* General views about nurse counselling. Specific views about breast care specialist nurse counselling.

* The specific role of nurse counselling for women at the point of choosing a treatment for breast cancer.

* Views about training in and efficacy of oncology counselling.

APPENDIX 7

Two Transcripts of Interviews with Nurse Counsellors

Interview NC 1

IK: If we just start - generally if you could give me a quick description about the medical practice in this setting, concerning the treatment of primary breast cancer.

NC1: Patients are referred by their GPs to a new patients clinic. At the new patients clinic the patient has, usually, a fine needle aspiration cytology, and she's already had a mammogram done. She returns to the clinic on a Wednesday and the results of cytology are given to her. And she then comes to the unit for staging investigations on a Thursday or a Friday. Staging investigations consist of chest X-ray, bone scan if the lesion is 3cm or over, or if she's got an M1, blood biochemistry and the doctor examines. If her liver function tests are distorted then she has a liver ultrasound. So, or she can come via the breast screening clinic where well-women are picked up, maybe asymtomatically. And they come through our assessment clinic on a Wednesday afternoon where they have immediate cytology and again they come in for screening, for staging in the same way.

On a Tuesday morning decisions are made about their management following their staging investigations. Management rests obviously on many things but generally speaking a patient with a lesion of under 3cm and no further evidence on the mammogram of microcalcification is eligible for wide local excision, axillary node sample or clearance (there is a sample clearance trial ongoing at the moment) followed by radiotherapy, if the margin of the lesion is clear. If the lady is pre menopausal she will be offered, and node positive, she will be offered some sort of systemic treatment. Either chemotherapy, six courses of CMF, or ovarectomy or injections of zoladex 2, to chemically ablate the ovaries. If she's node negative or post menopausal, regardless of node negativity or positivity she's offered tamoxifen, 20mg a day. If she's 3-4 cms she may be offered to go into the pre systemic trial. I'll talk about that more in detail in a moment. The outcome of her treatment would be she would be randomised to pre systemic treatment or with wide local excision and nodal procedure and radiotherapy after her pre systemic therapy or immediate conventional treatment, breast conservation, as I've described.

If she's more than 4cm but not T4, so T2, T3, she would be offered - and under 70 - she would be offered inclusion in the pre systemic trial where

the ladies are randomised to conventional treatment, that's mastectomy, with or without reconstruction, axillary node clearance, radiotherapy if there's a lot of lymphatica or vascular permeation, or if the lesion has been attached to the muscular facia. The pre-systemic treatment consists of a wedge biopsy to determine histology and oestrogen receptor. Pre menopausal women are offered, if they're oestrogen receptor rich, they're offered injections of Zoladex and they're over-viewed for - well, or Zacraphosbite, Adriomycin and 5FU, so the pre menopausal women who are oestrogen receptor rich are offered ovarian manipulation, observed after 12 weeks, that's three injections, three [ ]. If they've responded to treatment, if the lesion has shrunk then they go on to have another one course, I think, of Zoladex and then mastectomy, with or without reconstruction and at the same time are followed by ovarectomy.

IK: That's T4 women...?

NC1: T2 or T3, this is pre systemic. They're randomised to either conventional or this. If they agree to go into the trial obviously. If they do not respond to hormonal manipulation they will then have four courses of CAF, then their mastectomy and then another 2 courses of CAF. If they're oestrogen receptor poor they'll go directly into CAF. If they are post menopausal they will have the same chemotherapy but their hormonal manipulation will be Tomoxopin and observed after 12 weeks. If they become static on hormonal manipulation then they would go on to the chemotherapy. If they remain static on the chemotherapy they would go on without finishing their course, or if their lesion started growing they would go on to have mastectomy. The ladies who are post menopausal continue on - who've been hormone dependent and have responded to Tamoxifen continue on Tamoxifen. There's a debate about whether all ladies should have Tamoxifen and that hasn't been finally decided on yet. T4 ladies have usually a wedge biopsy to determine oestrogen receptors. Pre menopausal women usually have a Hickman line inserted and they have 12 weeks of dose intensive chemotherapy. In fact the side effects from that are much better than they used to be. The ladies usually lose their hair but they're not usually sick and many of them work while they're actually having it. So dose intensive chemotherapy means continuous 5FU via a continuation administrating pump plus a bolas of Adriomycin every week or if they're post-menopausal and oestrogen receptor rich or T4's may have Tamoxifen. What happens locally depends on how they've responded to the dose intensive chemotherapy or the Tamoxifen. They may go on to have a wide local excision. If they haven't responded very well they'll go on to radiotherapy. If they've responded very well they'll have wide local excision, axillary sample, usually clearance and radiotherapy. If they've responded partially or if it's been a very big tumour, there's still quite a lot of tumour bulk there then they'll have a mastectomy usually with Latizmous dorsi flap reconstruction, or Latizmous dorsi flap to ensure a good skin margin to close the gap. Over 70's have a wedge biopsy and depending of oestrogen receptors they go on

to Tamoxifen. If they have no oestrogen or low oestrogen receptor they have surgery, if they're not T4, they have surgical either wide local excision or mastectomy. If they have got oestrogen receptors then for 12 weeks they'll be observed with the Tamoxifen. If they are static or progressing they'll go on to surgery. If they're responding then they'll continue on Tamoxifen and remain under observation.

IK: That's a wonderful overview and demonstrates just how complicated the treatment for primary breast cancer still is. Now maybe that will lead us to the next topic and that is who in this place gives the information to the woman about diagnosis and treatment, when and how?

NC1: Generally speaking the patients come to either the Wednesday morning clinic or the Monday. The Monday afternoon clinic, if they're clinically and mammographically positive, although it's a new patients clinic they will tell them that they probably have cancer and they will arrange for them to come in on a Thursday for staging.

IK: The consultant will?

NC1: The consultant will. The consultant will usually ask the nurse counsellor to see the patient at that stage and the nurse counsellor will ask the patient - if she's with the doctor then she doesn't have to do this obviously but what usually happens is that the patient comes after she's seen the consultant and after she's had the final aspiration cytology done. The nurse counsellor will say "what did the doctor tell you?" and the nurse counsellor will try to elicit that the patient understands that she **has** cancer. If the patient is obviously blocking that she's got cancer, the word, the nurse counsellor doesn't usually go over these barriers. If she's saying "oh it's the nasties" or anything the nurse counsellor will try to elicit from her that she understands that yes it's cancer but if she's not admitting to anything then the nurse counsellor doesn't go over that barrier at the moment. She will probably then let the ward know that the patient doesn't seem to understand or isn't acknowledging that she has cancer. Nurse counsellor will try to see what the patient's perspective of cancer is, although often she's very much in shock at that stage. She will try to see if she knows anybody who has had breast cancer which can colour her views, and she will try to point out hopeful aspects but will not falsely reassure. She'll offer Breast Mastectomy Association literature if the patient wants it at that stage although it's a little early and she'll explain about staging procedures. If the patient tries to start asking too many questions about treatment then the nurse counsellor tries not to be drawn into discussion about treatment because the patient just gets overloaded with information then. The nurse counsellor also should try find out what the patient's support is like at home and how, if the partner or husband is not with her, if there is a partner or husband, how they will be and the family will be and offer support to them also. She'll try maybe at this stage, maybe on the Wednesday morning, or maybe when she comes

in for staging, to find out if there are any financial problems or immediately if there are any family problems like elderly people to be looked after or young children to be looked after. So that could either happen on the Monday or the Wednesday when the patient comes back having had a biopsy or a fine needle aspiration done, biopsy in the ward, or a fine needle aspiration done at the clinic so again the same thing happens. If the patient comes through the assessment clinic then usually the nurse counsellor from the screening clinic will see the patient. Then, or if it's not appropriate then the nurse counsellor will see the patient. Then the nurse counsellor sees the patient while she's in staging. At that stage the nurse counsellor will have looked at her notes and will have ascertained the size of the tumour, what it's been staged at T1, T2 etc. She will then see how the patient's coping, if she's sleeping, try to assess what stage she's at but it's really very early days still at that stage. See how the family have been and open a few doors as to types of treatment that might be available, obviously speaking generally, but it's helpful if the patient might be for breast conservation just to go over a little bit about what breast conservation entails. But always classifying it that the doctors discuss each individual patient on Tuesday morning and that it's then that decisions are made depending on the results of their staging investigations. While she's staging she will also try to ensure that she says to the patient that somebody from the community will come and visit her because we usually refer to the Health Visitors in the community and if the patient objects then we write on her card 'no Health Visitor'. We'll also offer her written information from Breast Mastectomy Association and tell her about self help groups and relaxation classes in the Western here. The self help groups are local, the relaxation classes are in the Western although there is a self help group in the Western.

Then on a Tuesday morning the patient comes and it's at that stage the consultant - what happens is that all the consultants and the registrars etc. meet, each individual case is discussed with looking at mammograms and the team make a decision about how that person's going to be managed and written on her staging sheet is what the proposal is.

IK: So that's before seeing the patient again, they meet again and deciding upon the treatment according to all the information they've collected.

NC1: Right. So that's at half past 8 in the morning and then at half past 9 the patient's come and so the doctor that's most likely to be looking after her then has an interview and discusses with her and whoever is with her what the treatment is going to be. Then the nurse counsellor tries to see her to ascertain whether she's understood this, whether she's understood that she's in trials if that's relevant, ensures that she knows what date she's coming in for treatment if she's coming in for surgery.

IK: That's usually a week after diagnosis, isn't it?

NC1: It's about approximately a week to 10 days after her first visit.

IK: That leads us to the next topic and that is the policy in the place, philosophy, concerning giving women the possibility to participate in the decision-making concerning their treatment. What usually are the decisions given to the women and who actually presents the choice to the women?

NC1: Well in some cases there's not a choice in treatment, there's only a choice in having or not having treatment. In the very odd occasion when the patient does not want say surgery, then the surgeon or the radio oncologist will negotiate with her what type of treatment she might accept and that usually takes a few sessions. I think I could count on maybe two hands the number of people in the 12 years that I've been here who've decided they didn't want the treatment that was offered to her.

IK: Actively said...

NC1: "I don't want treatment" or "I want to have holistic treatment" etc., so these are a very small group of people. Now if the patient is, now sometimes there isn't in fact a choice. Some people for example, they've had a biopsy and the lesion has been excised and they electively have decided, because it was a low grade type of tumour - oh there is another trial which we'll go into that in a minute - if the patient is electively having a node sample and then will be having radiotherapy so the doctor, probably the radiotherapist will explain these factors to her but the nurse counsellor will say "do you understand the treatment" and "do you agree with that type of treatment?" but there hasn't been a sort of choice given to her. The nurse counsellor infers by "are you happy with that, do you understand and are you quite in agreement with that" that if she wants to make objections then she should do so. If the nurse counsellor is concerned or she doesn't think that the patient really is understanding or at ease with the situation then she'll go back to the surgeon or the oncologist or radio oncologist and discuss it with them so she'll try, she will try either before the patient leaves the clinic that day or as an ongoing thing before the patient has any specific treatment, she'll try to ensure that the patient then comes to terms with what's been decided for her and agrees with it.

The treatment, I mean mostly the choices lie in "will you have reconstruction or not?" if it's mastectomy. If it's pre systemic treatment "will you participate in the trial or not?". If it's axillary node sampling or clearance, because there's a trial for that, "will you participate in that or not?".

IK: How about the surgical procedure, really the decision whether to have a mastectomy or lumpectomy...?

NC1: Oh no, well that, the decision to have surgery, I mean obviously some people are not eligible to have lumpectomy. The surgeons, I think in fact we have moved away, rightly or wrongly, I mean normally the nurse counsellor says in her discussion with the patient when she's at staging, she explains to the patient that if she's under 4cm, could be eligible to have just breast conservation, explains that through trials we've discovered that mastectomy and breast conservation are equally successful. Usually at that stage the patient is already beginning to voice whether she's... you know there's a lady in at the moment for example who said all along that she didn't want to have wide local excision, she wanted to have mastectomy. So, whatever anybody said, and nobody would try to steer her away from that. The surgeon would try to say "well they are equally successful, do think about it, the chances of successful treatment are equal with both" but if she chooses to have a mastectomy then they'll go along with that.

IK: So this is really some times a situation where the patient **has** a choice?

NC1: Yes. But what we've moved away from, when we first started doing wide local excision and I would say probably up until very recently and often and sometimes still we say the choice between mastectomy and lumpectomy are equal. If you have a mastectomy you won't have radiotherapy afterwards. If you have a wide local excision you will have radiotherapy afterwards. If you wish to choose to have the mastectomy then the surgeons will discuss that with you and go along with that. You've often, rightly or wrongly gleaned, I mean sometimes the patient says "oh I hope it's not too drastic" and you say what do you mean by too drastic? because sometimes you might think "Gosh does she mean she's going to die?" But no, she means, maybe it's a mastectomy or one was using the phrase "I wonder if its going to be the big job" which means the mastectomy. So often the patient on the Thursday or Friday when she's at staging will have begun to say well really I hope I don't have to have a mastectomy or, I'd really rather have a mastectomy but usually she leaves the, usually the surgeon will say or the radio oncologist will discuss this and we've discussed this and you would be eligible, we think the treatment that would be suitable for you would be such and such and the nurse counsellor on seeing her again would say "are you at ease with that decision" and hopefully the patient yes, agrees with it. Other decisions that could be made are that if they have, having had excised they have either in situ disease or a low grade type of cancer, like tubular cancer or comedal type or cribo form, well differentiated tumour then she might be asked if she will go into the trial which randomises to surgery alone, surgery plus Tamoxifen, surgery plus radiotherapy or surgery plus radiotherapy and Tamoxifen. No chemotherapy. So she might be included in the decision-making about that. Mostly the decision-making is whether I'm going to have a tissue expander or a reconstruction or not and if I'm going to have a flap whether I have a prosthesis put in or not. I mean obviously whether I'm going to have treatment or not. Whether I'm going to enter the trial,

whether I'm happy about having just the wide local excision and not the mastectomy, if I'm going for dose intensive chemotherapy am I happy to have that or would I prefer to negotiate other types of treatment. These are the sort of choices the patient could be faced with.

IK: Sounds a lot of decisions.

NC1: Well obviously each patient, well no patient has all these choices. Usually a patient really only has maybe one or two choices.

IK: It's taking us a bit backwards, but what sort of emotional support is provided for the women at that stage? Although you've talked a bit about it.

NC1: Well the emotional support that is provided at that stage, I mean if... The nurse counsellor gives the patient her card and invites the patient to phone if there are any problems. Usually at that stage the patient is really coming to terms with the diagnosis and there is undoubtedly, they do go through a sort grief process. If the patient is really, usually the seeking of help comes from the patient. Because of the degree, the amount of work we have, we have to be... I mean we will phone a patient up if we're very concerned about her but normally because she is moving through the sequence we will be seeing her again when she comes into hospital so we won't necessarily be loading emotional support at that stage. We will note that she is very tearful and in fact we will be **relieved** if she is very tearful because if she's very tearful at that stage she's usually acknowledging the fact that she's got cancer and she will start moving through the grief process naturally herself. It's seldom at that instance that we invite psychologists or psychiatrists to see her because we really have to ascertain what stage she's at and we must allow her to do all her worry work and her grieving naturally. If she gets stuck later at any of these stages then we will probably either follow her up more closely ourselves or ask the health visitor to follow her up more closely, or make notes and think she needs to have psychological help or psychiatric help. Does that answer the question?

IK: Yes. Maybe going back to the decision-making idea, maybe you'd like to talk a little bit about your personal experiences with women who are going through decision-making, maybe on the line of what is your experience, who are the women who were better at really making such crucial decisions sometimes and who are the women who really were very difficult about it? Is there something you think you can think about?

NC1: No. Everybody is different. I mean the elderly are not, often the elderly are not very happy to make decisions about whether they're going to be in a trial or not. They really like the doctors, in the main, to make the decision for them. People who again, it's really text book stuff, it's quite, very interesting, that all the people who are risk, people who are alone,

people who've recently had a bereavement or recently had some sort of emotional upset like the death of somebody or a divorce or sometimes even moving house, all these sort of losses, are in a bit of a turmoil and may find the burden of making a decision about their treatment just too much for them. We try **hard**, because we've learned again by our mistakes, we try hard to ensure that the patient has time to think about things and not to, to try, if we feel they're not, they're really still fluctuating between one choice and another, we try to say you do need more time, we offer them other people to talk to, have been through either one of the choices of treatment say. We, if the surgeon says right come in tomorrow for your operation because there happens to be a cancellation, we try to say look she hasn't had time to think about things, please don't. That doesn't happen very often but I can think of one glaring example where it did happen and two or three years on is saying why did I have to have a mastectomy when she actually only had in situ disease. At the moment we have a GP going through our hands who's a young GP, because of her, she's a victim of our own knowledge, as we often find medical people are often the victims of their own knowledge. They will go and seek out all the information. They will have had experience but only a narrow experience of people where things have gone wrong. They haven't had the broad experience of people who have done fine because they're not the ones who need help, so there is an example of a GP at the moment who is going through and she's oh dear, needs, well treatment has been suggested to her and well she's not swinging any more, I would say, she's been talked to a few times by the consultants and, they're very good at not pushing their, they're good at giving the choices and putting all the aspects forward to everybody, and she said I really can't make this choice and there was a sort of suggestion that well she was aestrogen receptor positive and perhaps marginally it would be better to have ovarian manipulation, like an ovarectomy. She wanted more children because she has a handicapped child and she's got two normal children, although she's in her upper 30's. I was concerned about her last week for example, and I thought really she wasn't ready to make decisions but she's now talking more clearly about well, if I had Zoladex I would still have to have an ovarectomy and then it would be too late for me to say I wanted CMF, I really don't like drugs, so she seems to be talking through it to herself although her husband is actually having a slight influence saying I think you should go for that. I think she is coming to terms and I'm not so concerned about her now because she's making the decision on her own, she's talking it all out and she has had a bit of time to think about it now.

IK: So you talked about elderly people having difficulty...

NC1: And people alone. They're the ones who have most difficulty making decisions.

IK: Did you hear very often the type of saying "I prefer the doctor to make the decision, I don't want to make a decision, he's the one with the knowledge and the experience". Is it something you've heard regularly?

NC1: Oh yes. Very common, and I think it's a justified comment, particularly working in a team like this where they are really fair in their giving of information and they're really fair in their giving of... I mean nothing is perfect, I know that but if the patient feels that she wants to put the decision into the... I mean the doctor will never decide whether she's going into a trial or not, the doctor cannot do that. That has got to come from the patient. If the patient gives permission for herself to be randomised saying that's OK that's fine, the doctor may well make that decision but it's been well, the patient has to sign a consent form. But if it's a choice of treatment and the doctor really... I mean the treatment is obviously the best type of treatment is this because it's been tried and tested through trials then it's fair enough that the doctor has had the experience and it's not just one doctor making the decision, it's the team of doctors making the decision, it's a multi-disciplinary team making the decisions so I think these comments are fair.

IK: From your experience, I'm just curious, would you like to point any connection of the attitude you know towards the influence of culture on the woman.

NC1: I wouldn't generalise, no. I mean the sort of...

IK: Do you understand what I'm looking at?

NC1: Yes. It probably, people who delve and are questioning, younger women who have been well educated, I don't mean well educated from academically well educated. They're young, they've grown up with a peer group of people who are used to, they're not in awe of the doctors, they normally will ask questions and they will often make decisions themselves and they've read magazines and literature themselves, so often whatever socio-economic grade they are - and of average intelligence - they will make decisions themselves and they will ask questions. I don't think, I don't really think, I think there is a difference in attitude to the disease in different, not necessarily generally speaking English, Scottish. I think there's a difference between the attitude of, generally speaking, upper middle class or middle class Edinburgh women to slightly lower middle class Edinburgh women or Glasgow women and Border women are usually very down to earth, Border women, Yorkshire women, Lancashire women. Women that come from the Highland areas are usually fairly well down to earth about treatment and acceptance of treatment and diagnosis etc. That's a personal observation but I would say that would be an interesting one to look into.

IK: Maybe now, onwards to counselling. What is really, after your 12 years of experience in counselling, what is your views about counselling in general and about specific breast care specialist nurse counselling? How can you summarise it?

NC1: I don't like the word counsellor too much because people actually still, not so many, women who've not had any experience of the word counselling and in some cases some people think of counselling being in a punitive type of sense because if they've been off work then they may have counselling "why are they having so much time off work", or sick leave, or if they've done something that's been frowned upon at school or in student life or at work again they could be counselled for that so the word counselling may have different connotations. To somebody who doesn't know too much about counselling, again you can't generalise about women, hear the word counsellor and say "no, no I don't want counselling", imagining I think but again I'm maybe not correct in this, imagining that this person is going to sit down and talk great deeply to her and delve into her inner most soul. I would say that the Egan method of counselling which is asking open-ended questions and reflecting back questions and not assuming anything when the patient is talking to you, that sort of counselling which isn't obviously counselling is what the breast care specialist should be doing. She should be, if there's decisions to be made, she should be reflecting back questions to the patient and trying to get her to come to a decision herself. If she's got other problems, I can't give you examples off the top of my head, but if the patient comes in a greatly anxious state and all sorts of things tumble out then if she's a well skilled nurse counsellor she will pick out the specific points and she will say right, let's try to talk about that. I hear you have problems with your husband or I hear you have problems with your teenage children, we'll talk about that in a minute but be aware of the fact that she is not the - that patient is there for her and the nurse counsellor's responsibility is to deal with her breast cancer and anything that's involved around that. If she's been having marriage problems, for example, long before the breast cancer ever came up then she should not burden herself with the problems of that but she should direct the patient to the right area to seek help, or if it's teenage problems then she, if it's a teenager who is worried about her mother then that's different, the nurse counsellor may be asked to speak to the teenager, but if she's a renegade teenager maybe the nurse counsellor should speak to guidance teacher, ascertain if the teenager and the mother wish her to be seen or him to be seen but shouldn't try to do any work with that if it's not in her role. So I see the role of the counsellor as an information giver, a patient's advocate, a monitor of her progress, this is in the ideal world where you do have time to see the patients through, and slightly more in-depth counselling in the listening method.

IK: For example which methods do you use?

NC1: I use the Egan method all the time, I find that that's...

IK: And Rogers?

NC1: Yes. I find that, if the patient comes to me or is referred to me, say she's either not looked at the scar, her body image is damaged, or sexually she's having problems, she's having problems with her own self worth or she still has some sort of phobia I will see, if the patient is referred to me I will see the patient and I will try to ascertain you know I'll try to get a background of the patient, may go back 10 or 15 years and I'll try to make a bargain with the patient that I'm going to speak to her for, she has an hour with me. This is really relatively unusual because we don't go on and on and on with patients. You may have 2 or 3 patients that you have an ongoing relationship with but your time does not allow you to see patients maybe every month, or see 4 patients every month for an hour each, it's not... So you may see the patient on, if I haven't, if the patient , you say do you feel that you want to see me again and if the patient says yes that's been helpful just talking to you, I've thought it all out myself, yes I'd like to see you again, then you offer the patient another session in a month or so. If you feel that the patient again is moving on and not going over the same ground, but is deciding herself that things are coming on and you offer her another session. Now if after 3 sessions she's still wanting to keep hold of you then you will either make the, you'll offer to see her but in a couple of months or so or assess whether you're the appropriate person to be seeing that patient and you probably will phone the patient, if you've made a bargain that yes the patient is going to come back to you afterwards, the patient will come back to you if she needs to. You may say well would you like me to phone you, because some of them are a bit shy about phoning, so you may make a bargain that you are going to phone them but usually you'll let the patient do the contacting. You let the Health Visitor know as well if she's been in touch with the patient.

IK: Now I just wonder about specific nurse counselling at the decision making, really the actual counselling role that you see yourself doing at the decision making, I mean actively. If you could recall some specific situations or...

NC1: Well actively you try to ensure that the patient has all the facts and you often ask her to repeat the facts to you to try to ensure that she does understand what decisions, what the alternatives are. The patient usually then comes to the decision herself. If she's having a problem deciding, then certainly never, I mean if she says oh I really can't make up my mind about say tissue expansion what would you do? you obviously don't say I would do this, you say well I really don't know what I would do because unless you're faced with something you can't make up your mind. You talk around the pros of breast reconstruction and the cons and you offer literature and you offer to ask her if she wants to see people or talk to people who have had these treatments...

Sometimes the surgeons are really, occasionally say oh yes have a tissue expander, it really doesn't do you any harm, I'm sure you'll enjoy it, then that's a difficult one because often the nurses know that the patient really doesn't want it and she may then say to the surgeon "look she doesn't really want it" but by that time the patient is prepped and ready for theatre... so sometimes it's better then really to say nothing because it's a bargain that's been made between the surgeon and the patient and nobody's right. We have a patient for example, who did get a tissue expander in although she hadn't actually consented to have a tissue expander in and there was a bit of a - not a stromash about that because she wasn't a stromashy type of girl. We were concerned about that but in fact she actually is pleased that she did have the tissue expander put in. On the other hand we had a woman who said all along that she really didn't want one but her husband influenced her and the surgeon said she probably should have one so she did go along with it despite our better judgement and she's actually asking to have it out now very shortly after she's had it put in. So there's these sort of things.

As far as trials are concerned... again you never try to put words into the patients mouth. Really usually the patient does come to the decision. What the counsellor can do is buy her time and say she's really not ready for a decision and maybe go to her house and discuss things with her and ensure that the patient knows that she doesn't have to make a decision today. If it's a case of like an old lady at the moment who's been going through, each time she comes to the clinic her Piaget's disease has deteriorated and she's now got a lump and the surgeon really thinks she should have a mastectomy but she's resisted and resisted and resisted so I went to the house and her daughter-in-law was there and discussed all the aspects with her and tried not to influence her and said that you know we'd still keep an eye on her if she didn't want to have a mastectomy but she has come round to saying she would have the mastectomy but then discussed it with her family and I said there's no urgency, it can be done at any time. She went away and stayed with her son for some time and I think she's come back in a much better frame of mind so the counsellor can buy time for them to make decisions.

IK: And maybe sometimes give reassurance that you don't have to make a choice and that you don't have to feel under pressure.

NC1: Yes. Again if its a trial then she has to make the decision is she going into the trial or not and if she doesn't want to go into the trial...

IK: But again ensure hat she's OK about not going into the trial.

NC1: Oh yes. Yes, I should have said that. Always when we're talking about trials we say "don't be altruistic, think of yourself, it doesn't matter, your follow-up will be exactly the same if you do or don't go into the trial.

There won't be anything said about you if you decide not to go into the trial. Yes. And your treatment will be equally good".

IK: So would you say that in your counselling role as a whole the decision-making aspect takes as a certain area?

NC1: Oh yes, of course it does, very much.

IK: So you see that as an element of your work that one should expand?

NC1: Yes.

IK: And maybe that again leads us to the last topic that I would like to discuss and that is really your views about the training in counselling and to the efficacy of counselling. This is a very major, you know, both major things which are of great debate. What do you think about training?

NC1: I think without doubt anybody who is in the post of nurse counsellor should not just be a nice person. She should have had experience and done a counselling course, this is me who had not done a counselling course but that was the way it was in those days. I think that anybody who is dealings with a patient in any sort of consultative way, the doctors as well should have done some sort of counselling because it would help them with their communication with the patient and it would help them to use their time properly and not to assess wrongly what the patient's message is but that's a little way off I would say but I would say yes it's important that people that are employed as nurse counsellors should have done the breast care courses. Either had a lot of experience in a breast unit and they are few breast units or she should have done one of the breast care nurses courses which incorporates a vast overview of treatment of breast cancer, the psychological implications, surgical implications, oncological implications, everything to do with the breast and some counselling as well. She should probably, I haven't got a curriculum of all the breast courses so I don't know what the counselling input is of the breast courses. I think they're fairly good, I think the Marsden one is very good. So yes, she should have done a course before she is appointed. And we're hopefully going to get a full time appointee some time this year. I have somebody part-time with me but she came from the ward and is very, very very good and I wouldn't think she could be faulted in any thing that she does and she has actually done a counselling course but I think AT's findings will probably elaborate on the vast differences between the training of nurse counsellors and the vast differences of the work that they do.

IK: So maybe just a last summary about the efficacy, do you believe that it's efficient?

NC1: Well you've got to listen to what... it's really difficult, well you've got to listen to women say but you've got to listen to trials as well. I mean the trials as you know and the first trials that were done when PM had the idea that nurse counsellors would be a good idea didn't show that there was any reduction of psychological morbidity or psychiatric morbidity but it did demonstrate that it was picked up more quickly, recognised more quickly and therefore treated more quickly. I mean LF's 1985/6 findings were that yes, the counsellor did reduce psychiatric morbidity. Working in a place like this is different to working as an isolated counsellor in a general ward because you know the whole team actually unite with each other, they all have the same policy, they all understand what the patients problems might be and are all well versed in being able to refer to psychologists or psychiatrists or to the counsellor or to help with Breast Care Mastectomy association or anything like that so the counsellor in this unit has a different job to a counsellor like AS who is working on her own on the community.

Interview NC 2

IK: Maybe we can just start, if you can give me a brief description of the medical practice in breast cancer that is happening in this setting. Basically what is the medical practice?

NC2: Well there are four general surgeons in this hospital and only one of them holds a symptomatic clinic for ladies with breast conditions, so I work closely with that surgeon who holds this clinic, which is a weekly clinic. Other surgeons see their patients as they crop up in a general surgical clinic, so there can be bowel conditions followed by varicose veins, followed by ladies with breast lumps and so on so I'm not available there at those clinics. So my involvement really is just with the one doctor who does that clinic. So at this clinic ladies are interviewed and then examined by the surgeon. Thereon, if the surgeon feels it's appropriate, a fine needle aspiration is performed, and then X-rays like mammography, pelvic X-rays are arranged and the surgeon, if he's clinically suspicious that the lady has a breast cancer, then he says so. That's when you can see women just going to pieces really.

IK: He says to them?

NC2: He says to them, if he's suspicious. So I'm in on this interview. I can hear what's said at the interview and then I take the lady and whatever relative or friend is with her, to one side into another room in the clinic and just go over again, ask the lady what she's understood about what's been said and clarify that I know she's on the right wavelength sort of thing and just get her general reactions and feelings about things. Obviously at her interview I introduce myself to her first, give her a card which I carry with me and let her know that she can contact me at any time that she feels she wants to. Then I explain to her, if she doesn't already know, what's involved with a mammogram, I'll explain what to expect because from that clinic, from this situation that she's in she goes upstairs to have these X-rays done. Where it's clinically positive the surgeon, although he's just done the needle test, he does expect them to have a mammogram on the same day which is relatively unusual. That's unusual.

IK: And that's done here?

NC2: That's done in the hospital in the X-ray department. So I explain about all these other investigations that she's about to have done and then I offer to go to the lady's house to see her at home. If - that's with her permission - if she doesn't want this then obviously I don't go. But if she feels that she would like me to go along then I will arrange that there and then for some day later on the same week.

IK: Most women want you to come at that stage?

NC2: Yes. Now over and above that the surgeon that the lady has just seen works very closely with a specialist consultant who comes over here every week from the Western General Hospital in Edinburgh so we have got this back up service that the ladies are automatically referred to. If the surgeon suspects a breast cancer then he will refer that lady on to see this specialist about a week later.

IK: So it's one of the two consultants that we've mentioned before, they come over here?

NC2: Yes. Now by that time, in a week's time, that specialist, the Edinburgh one, will have the results of all the needle test, the X-rays in front of her, as well as seeing the patient. She'll interview and examine the patient again herself (she's a lady doctor) and then with the help of the X-rays and results she has she will then discuss with the patient the pros and cons of what plan of action is best for her. And so really in effect I look on it as a second opinion but it's not really it's a bit of collaboration between the two doctors. But certainly, there are times when they don't agree always on the appropriate form of treatment. They will obviously agree in course of time but sometimes the surgeon who sees the patient first has suggested a mastectomy perhaps and then a week later when the lady is seen by this second consultant, being a specialist in her right, then says oh I think we can get away with conserving the breast so she suggests a lumpectomy followed by radiotherapy. And then if that happens then she will inform the surgeon and they'll both agree on it before it's actually carried out.

IK: That is leading us to the next, sort of onwards. Maybe you could tell me a wee bit more who gives the information about diagnosis, of treatment options basically, how is offered to the woman. Is it really at the clinic?

NC2: Actually the very first clinic the symptomatic clinic that the lady comes to, the one where I'm present at, the doctor seeing the lady in the very first instance is the first person to say and he usually does explain that nowadays - I mean in appropriate circumstances he'll explain that nowadays it's not always necessary for a woman to lose her breast and that with correct removal of the lump followed by radiotherapy treatment that the disease can be controlled. So that's the first seed that's planted in the woman's mind, that she doesn't automatically have to have a mastectomy because a lot of people still think this way, a lot of older women still think "breast cancer, I'll have to have the breast removed". So it's the surgeon who first plants that seed. Then, later on, if and when I see the lady within the next few days, I usually go over it again just to make sure that they're thinking of that there is a choice in the matter. But I feel quite honestly, this is a personal point, that I feel sometimes a choice or an option creates a dilemma for that woman. Often this seems to arise. In fact it's not long ago I said this to one of the surgeons that I feel that's it's putting the woman, sometimes, through a more traumatic, stressful situation that

some women can't, I think, some women can't cope with having a choice. I think a lot of them would rather the doctor said **this**. It's, I don't know, some people just can't cope with that. There was one lady recently who was referred to Dundee. Now the surgeon here had said to her "I'm sure, Mrs X, that this would be correctly managed having the lump removed" and explained that it's not always necessary to have the bigger operation but in her mind she was thinking she needed to have a mastectomy to get rid of it. Now when I went to see her at home I was thinking you know, her mind's think that, maybe for her that's the best thing. You see? Really it's difficult. So I don't obviously and never ever do persuade them in either direction but I was sort of expanding on the mastectomy side of it but this was before she went to see the second consultant, right, but in her case she was going to Dundee. By the time she went to see the second consultant in Dundee she had still thought Mastectomy and so that surgeon unfortunately didn't, that specialist unfortunately didn't seem to be able to take enough time with this lady and she came away out of that Out-Patient situation still thinking mastectomy until a nurse came along and apologised that the doctor had been taken away rather quickly and abruptly from the clinic and the nurse went over things with the patient and she came away from the hospital then sure that she would have a lumpectomy. Now this created a dilemma for us because by the time the lady came here for her surgery, the letter that was referred back from Dundee had mastectomy in it, that you know the doctor there had discussed this with the lady and the lady had wanted a mastectomy. So, however, I again saw the lady on admission here and by the time, at my interview with her I realised that this was how her mind was thinking, that it was changing, so I was able to inform the doctor that she had changed back again and that the content of the letter wasn't really the way that the woman wanted it to be. So he then went and spoke to the lady again and of course our doctor here in the very first place really thought that a lumpectomy was all that was necessary so that's in fact how it eventually was done, that she had a lumpectomy and she's away having radiotherapy just now. But that woman just, I think, was one person who needed somebody to say to her I think the best thing for you Mrs X is such and such. But she was left with the choice and couldn't cope with it and I felt that maybe I wasn't strong enough but I don't - no I would rather not make decisions but just be there to supplement and help them along and that was what I was doing but in fact I began to think that the nurse there whoever she is or was had actually influenced the woman more than I have and yet she's not a breast nurse as far as I know. It's amazing, but the outcome of that was good, was OK.

IK: You know, as you probably understood from my letter, this is really the interest of my study, this is the thing I'm most looking at and I've talked to women, that was the first part of my study, the idea of decision-making of the women and I would very much agree with you on some issues that yes, decision-making is a wonderful thing but it can create a lot of stress and I think you cannot ask anyone to go through the decision-making

process without having really the right amount of information and support and help and input that really can help a patient to go through it. Anyway, maybe, that is again, you really lead us in a way that is very, very helpful. Maybe you can tell me a bit more about the policy of this place, or even the philosophy, if there is such a thing, concerning giving women the possibility to participate in the decision-making regarding their treatment and from your experience what are the choices given to the women?

NC2: Well really the only choice that we can offer is simple mastectomy which is usually done now, or the lumpectomy.

IK: Is it given as a choice to many women?

NC2: Yes. If the surgeon thinks it's appropriate, yes.

IK: You've met quite a few women who had really this decision to make, whether they would have a mastectomy or lumpectomy?

NC2: Yes. But we do not mention, it's not mentioned by the doctors before surgery, about breast reconstruction because the philosophy of the surgeons here in a District General Hospital such as this is, is that if a woman has to have a mastectomy it will be done and then if that lady cannot cope with her altered body image or feelings of loss, whatever, then about a year, 10 months or so onwards, later, she will or can be referred for breast reconstruction then.

IK: Very interesting.

NC2: That is the medical staff's philosophy here and I have to...

IK: Do you agree with that?

NC2: No. Not particularly no. I think it's better that a woman has mentioned to her beforehand about breast reconstruction so that if she wants to have the surgery done all at once, which can be done as you know in Edinburgh. They can have the mastectomy and the breast reconstructive surgery done under the same anaesthetic, then if she wants the lady should have that option. That should be another option open to her but it's **not**. Now because of the situation I'm in, I actually do not, well very superficially maybe, mention breast reconstructive surgery to the woman when I first see her, initially, in the early days. But in so doing I have actually three women I could refer to you, one of whom is in Edinburgh Western just now having it done, who I had planted the seed earlier and they have referred themselves automatically to Edinburgh for that surgery. Because they wanted it done immediately. Now if I did that regularly then that would mean our numbers here would be dwindled. There's a lot of women who go to the Lothians for breast surgery anyway,

especially when the breast screening programme comes. I mean three years ago, two and half years ago a lot went to, chose, to go to Edinburgh for their surgery if anything needed to be done. I've got statistics that I could show you on that.

IK: So this choice is not given in this place?

NC2: It's not unless I mention it and I always mention it post-mastectomy, always, so that they mustn't feel they've lost something that they can't partially have back again.

IK: On the other hand, I have to tell you, I think I would agree with you against this sort of philosophy in terms of whether you can give the woman much choice. On the other hand this idea of giving the woman time to adjust to her mastectomy has a lot of logic behind and has proved in many studies to be of great value because then the woman is usually much more satisfied with the reconstruction. Because any reconstruction that is done is never like the original breast. Now if she had a mastectomy and then a reconstruction then she would be so delighted but if she had an immediate reconstruction then she would not be happy because she would always compare it to the original breast that she has just lost. Now this I've heard also from women, so there is a logic behind it but I think the important thing is to give a choice, yes.

Anyway going back to the decision-making can you tell me a bit more of the decision-making between lumpectomy and mastectomy and how is it offered, how is it presented and whether there are any other choices apart from reconstruction. Clinical trials I understand are not running in this place. But the choice about lumpectomy and mastectomy.

NC2: The only other choice and it's not really a choice, it's a decision in a sense that, for older people who are relatively unfit, they who are seen with a breast lump that is probably significantly cancer then sometimes they don't, the decision is for them not to do any surgery but to treat them with hormone therapy such as Tamoxifen. But I mean that's the only thing that I can think of. Well, the decision as to whether lumpectomy or mastectomy really I suppose again, it must be on a clinical basis of what the doctor finds, the position of the lump, the size of the lump related to the size of the woman's breast as to whether it's a feasible thing or not. I mean, if there's a big tumour behind the nipple and it's so central that by the time they've taken the whole lump away, the nipple's away and the breast is terribly distorted and then followed by radiotherapy it'll be shrunken even and wouldn't be a pleasant sight for the woman to have to live with. I think - that has happened, I mean I've seen the results of that and it's not the nicest thing to have to cope with. But that's where I think in some cases perhaps the wrong decision - I mean I don't know the details I've only had to come along and fit prosthesis to try and cover up this and fill the bra in situations where a woman has had a, what I would

quote "a partial mastectomy" but whether it was the woman's choice, I think it was a medical decision actually just to do it but she's not happy with the result. However, it goes back to really whether the woman has an ample size breast in which case the lump can be removed without the contour of the breast being altered too much. But it seems to be if they take quite a bit of the breast tissue away and then follow it by radiotherapy the breast shrinks quite a bit and then if the woman puts on weight the other breast tends to get much bigger and then there's more of a difference in the size and they're quite unhappy with the results cosmetically. So taking - it's a cosmetic thing really. The doctors base it on, they try and look to what it's going to be like eventually when they're making that decision for the woman. They're looking at what they see her size and shape as it is and where they feel the lump is and whether it can be successfully removed and treated as a lumpectomy or wide local incision.

IK: From your own experience would you say that woman, when given such a choice, choose more to have a mastectomy or lumpectomy, when they're really offered a choice?

NC2: I think really they go for lumpectomy. But sadly another thing that I'm aware of, that arises quite a bit, they can gear themselves up for a lumpectomy having been advised that this is the satisfactory form of treatment for them and so they have the lump removed, 10 days later or so histology comes back and because of the type of cells or aggressive type of cancer that they've got or whatever the woman is then advised to have a mastectomy but that information hasn't quite reached her yet. Meanwhile she's on the programme for radiotherapy because she originally had the lump removed and she goes to Edinburgh for the start of her radiotherapy treatment and can be referred back here for mastectomy. Now that really doesn't arise too often but it can arise that, the instance I mention there was really a breakdown of communications. I don't get histology results, I'm fighting hard to get them so that I know what's going on or to know better what's going on but unfortunately a couple of these instances has happened where there's been a breakdown in communications between the two hospitals and the woman has been programmed for radiotherapy and has gone for the start of it only to be advised when she got there that "oh no Mrs X there's been a change of plan for you and you've to report back to the local hospital, they'll write to you as soon as possible to get you to go in for surgery". Now you can imagine what that woman feels, because all the plan has gone awry sort of thing, it's just all changed and she wasn't aware of it. So I've had one or two instances like that where I've had to pick up the pieces when they've come in to have a mastectomy which hadn't really been planned for in the first place but was advised on the basis of the histological results. So occasionally that can happen where the best schemes are not able to be carried out but it's not always because of any - it's only because the best advice, the original advice isn't the best so they've had to change and have a mastectomy and that must be quite hard for the woman to cope with. I

think it is when I'm dealing with them because their train of thought has thought "oh I'm going to get away with conserving the breast and I'm going to still have my breast" and then two weeks later, change.

IK: Do you know funnily enough, and now I'm sharing a bit of my... when I've talked to women I've heard a lot the type "I just want to get rid of the cancer, I want to have a mastectomy". That was something I've heard quite often.

NC2: But then there's no guarantee that they get rid of it by having a mastectomy.

IK: Of course we both know, because we understand that cancer is a systemic disease but let's face it many people who are not into the medical field or do not have a lot of knowledge in the area, don't understand that cancer is a systemic disease and they think it's a local, regional, sort of illness and that's why they think by having a mastectomy I get rid of the cancer. Have you had that view quite a lot when making the decisions?

NC2: Oh yes.

IK: "I'd rather have a mastectomy to get rid of the cancer" and that way they are also avoiding radiotherapy.

NC2: That lady - oh yes, yes - now I've met one or two, not many people, who would prefer to have a mastectomy to avoid radiotherapy but in the short time I've been doing this job I've met just about a couple who are really adamant that they did not want radiotherapy and one of the most recent ones had actually ended up having a bilateral mastectomy because of that but then she wanted to be the same. She'd already lost a breast and when this unfortunate situation cropped up on the other side she had decided within her own mind that although the surgeon said to her now we could remove this cancerous lump by just removing the lump and have radiotherapy. Oh no, she said, in the first place I'm terrified of radiotherapy, I do not want radiotherapy and I'm quite happy to have the other breast removed because it will be the same. So that's how she coped with it. But everybody copes in different ways.

IK: To sum up this idea of decision making, this is really the focal point of interest for me. What is your experience with the process of decision-making, when women are sitting there in front of you, how do you know if the woman's made up her mind, if she's quite clear about it or if a woman is really swinging about in her mind? How do you assess? what is your experience with women who have to make such crucial decisions?

NC2: It seems maybe strange for me to say that I feel that for it to be left for the woman to make a choice, that these situations here with us - I might be wrong in this but my impression is that they are few. They're actually,

that bit of what I said before was that it seems to create a dilemma in their minds but these situations are few, there are fewer of them, where it's left to the woman to actually make up her...

IK: To really go home and think about it and come back...

NC2: It either is that they decide on what's first said to them in the clinic at the very beginning that they latch on to, that 'well we think we can treat this without having to remove the breast', so that is a fairly positive statement from the consultant and that's what they go on really. Either that or the other thing happens where it's a change of plan, necessitated by the histology so again the decision is taken away from the women in these situations. But the few in the middles who really have to go home and decide, I find that that is putting them in a really stressful, additional stressful situation because they really want somebody else to make up their minds for them. In fact I quite, occasionally I'm asked 'what would you do?' and I feel well I'm not in their situation, nor have I been so it's not easy to answer that because they're the people who have to make up their own minds.

IK: But did you find also women that said 'but I have the right to make this decision, it's my body'?

NC2: No. I find that the people here in this area really don't seem to have that feeling. I don't know what it is but they don't react like that in Fife. Whether it's Fifers or Scottish people but there seems to be a difference from what I've heard about and **read** about but Scottish people or from this area don't seem to have...

IK: Somehow a fatalist attitude maybe?

NC2: I honestly - whether it's upbringing or what I don't know, but they seem to cope better for example. I think they appear to cope better, I hope this is true but of all the few hundred women that I've known of since I've been in this job, I mean they've all got my card but comparing with the crisis phone calls that nurses deal with in the South of England for example, I feel I don't get all these crisis calls and I sometimes wonder if this I should take personally, I hope not, but I feel that I'm giving the women as much information as I possibly can, I make up an information pack which I can show you with various helplines, not just mine but Cancerlink and self-help groups locally and nationally and sorts of things and you know they're not really interested. Some of them I know when I do a post discharge home visit after surgery I refer to something in the pack for example to do with bras or whatever, they've never looked at the thing. They go home and they cope in their own ways.

IK: That's very interesting. Do you think it has to do - I can relate to your observation and actually I write about it a bit because I came to a very

similar view on my little sample of women I've talked to but do you think it has to do with maybe the influence of the Church in Scotland or the family system or with what could you connect it to really?

NC2: I don't think it's religion anyway because religion doesn't seem to come into it. I ask or find out what religion people are but it doesn't come into their lives. Very few people, people that I've been dealing with they either don't go to church or don't appear to have. I don't know it's strange but I don't think religion is anything to do with it. I honestly don't know what it is. Whether it's a good supportive family environment might have something to do with it because the people that do come back to me more and more are the people who live alone whereas if they've got some supportive family contacts they don't **appear** to need the same support.

IK: I would think that's everywhere.

NC2: Yes, maybe that's everywhere. I don't honestly know. Whether it's our makeup bit that 'we'll manage somehow'. I mean I can remember - this is on a personal note and nothing to do with breast cancer but I lost my mother about 5 years ago and I know that, I mean I'm an only one, I've got very, very few relatives and the few relatives I have are all abroad so I think the staff here who knew me quite well wondered how on earth I was going to cope with this. But do you know I just made up my mind I was going to come back to work as though nothing had happened and get on with life. I had to, I've got to and I did. And I think maybe there are more of my type out there I don't know. But it's just in our make up or something.

IK: So different from much that is written in the text books.

NC2: Put it this way, there are three patients with possible breast cancer in this ward at this moment. One of them is German, originally German, a terribly nice lady, she is married to a Scot and living here, had lived here for years but you know her reaction yesterday, after the surgeon had seen her and said again to her that he was quite sure that this was a benign lump, she overreacted to his final remark, which was meant to be reassuring, meant to be, but he had said Mrs X "I see no reason why you won't get home after your operation tomorrow" and by the time I came along just minutes later she had just gone absolutely really quite distraught about all this. I said to her to tell me what did the doctor say, what's upset you. Oh she said, I'm going to be discharged tomorrow night, I might not be fit. I said and reassured her that she won't get home unless she is fit and able. "If you don't feel well enough they'll keep you overnight till the next morning". Now the other two were Scottish and no problems. It's just a different makeup, I don't know. But her reaction to an incidentally quite a simple thing, that doctor was intending to be reassuring but she just overreacted to just that one little thing, not to do with the breast lump but to her early discharge. I mean I tried to explain

that this was him trying to be reassuring that she wouldn't stay in hospital a minute longer than she had to but for her it was the wrong thing to say. We're all different.

IK: OK, let's go on to the next sort of area I would like us to discuss a bit. Really what sort of emotions, psychological support is provided for women here. Formal, informal?

NC2: Informal. It's just the nursing staff and myself being available. Well my interviews with the patients are on informal basis. I would say informal, yes. It's just a quick introduction in the clinical area followed by an informal discussion in the patient's own home where they're much, if they want that as I've said already, where they're much more relaxed and they're in control. It's away from this clinical environment. They seem to be far more at ease in their own house and by the time I go out and meet them they'll have a list of questions sometimes written down that they want to ask.

IK: So you really in most cases go to their home?

NC2: Oh yes. If I'm involved when they first present at the clinic yes, then I do. Because I think it's helpful for most of them. I don't go if I'm not wanted but em...

IK: And the family are encouraged to be there.

NC2: The family can be there, the husbands can be there if they're not at work but then it's also interesting, sometimes they're on holiday and it's also interesting for me to note how they cope with this situation when they know I'm coming beforehand, some of them decide they'll take the dog out for a walk. In other words then I know that they're not terribly keen on listening to what's being said about this and about breast cancer.

I like when their husbands are there. But some of them choose not to be even when they could be, I've noticed that as well. But I would say it's all on an informal basis because no situation is any different from this one and it's generally over, if the lady says will I make you a cup of tea or coffee or something and invariably I agree to that so that they know that I'm there for that length of time, for the time take to drink whatever.

IK: And what about follow-ups? How do you organise the follow-ups?

NC2: Well it depends very much on what the treatment plan is. For example if they're coming in and they're having a mastectomy, we'll take that first, then after that home visit I'll see them in hospital on admission the day they come in. Then I'll see them roughly three times while they're in hospital. The second time is a post-op visit when I just try and see how they are and maybe they want to really let go and have a good cry and this

helps. Then this second visit I'll go over the information pack with them and I don't just give it to them, I go through the contents and explain. And actually they have the opportunity, for example the great thing is bathing costume. But some of them are not interested in that. I'll take anything back that they don't want to have in this pack and it's used for somebody else, you see. Anyway I go through this with them, all the helplines emphasised and all that sort of thing. And then the third visit I go over bras and prosthesis...

IK: The cosmetic element.

NC2: The cosmetic element that's right. Showing them what they'll be wearing for going home and reassuring them on that score and then the silicone breast prosthesis as well.

IK: So you're the one who does the fitting?

NC2: Yes. And explain that it'll be me that they see and so on and so forth. Then I do a home visit again within two weeks of discharge. Now usually I make it the second week but with some, depending on how they've reacted and whether they're going home alone and no other support then I'll go the following week. I mean sometimes if you get panic situations that, what ever I've described on the tape here doesn't happen I'll maybe do an extra wee bit or whatever, this has happened once or twice, depending on how they react to situations. Anyway so I do this home visit again and that's just to see how they've coped with being at home, how the family is coping and the husband is managing, just the general - I often look at it just to know that there is somebody caring and they sort of quite look forward to knowing that you are coming and then on that visit I'll then have more of an idea whether or not any other treatment is required, for example radiotherapy. So if they're not having radiotherapy then I'll give them an appointment to come for about 4 weeks time from then for a fitting of a prosthesis and invariably it means getting a different style of bra because most, it's a true saying that it seems to be in this country that very few women wear the right style of bra to suit themselves, to suit their shape. I heard that in 1992 at a study day in Edinburgh on breast cancer and it's been true the fact that most women need to buy a different style of bra. Not a proper mastectomy bra with a pocket in it necessarily but a good fitting bra.

IK: So that's usually the plan of follow-up?

NC2: And then thereafter it's just often when they come to a Tuesday clinic, which is an oncology check-up clinic then I say when you're in the clinic I'm always available on a Tuesday, I very rarely go out the building on a Tuesday, very rarely, so I'm always here if you want to see me, otherwise I'm in contact by phone. And occasionally I phone them up about 3 months later. I haven't really got into doing that rigidly yet. I'm

sort of not sure whether that does any good, to be honest, because they know you're there. I look on it that they can contact me if they really need to.

IK: But then the few women you are concerned about you would contact yourself...?

NC2: That I would, oh yes, keep in touch with.

IK: Now a bit into the idea of nurse counselling, specialist nurse counselling. Maybe just tell me your views about breast care specialist nurse counselling, what do you think about it?

NC2: Well I feel it is an important input for patient care. It's, I think in this day and age, helpful because I can see the way these wards are, the way nursing is going that they are so busy with other illnesses, other conditions, on these general surgical wards that I think it's a true statement that nurses are saying now, it's going back to the time when we were not allowed to speak to patients. Nowadays we're very much allowed to speak to patients but it's getting to the stage where there isn't time. So for somebody to spend time to cope with that patient's emotions, that woman's emotions through this stressful time is quite essential because nobody else is doing it. If you take a look at the patient profiles on the way out of this ward you will see that absolutely nobody writes down the patient's emotions, feelings, it's all 'admitted today from waiting list, TPR, urine analysis etc...

IK: In the nursing report?

NC2: The nursing report. There's absolutely nothing written about the psychological aspects of patient care unless I put my input in. It's a sad fact that that is - that's maybe peculiar to this place, I don't know but it's a general thing on all the surgical wards anyway. That it's not really identified. So therefore there's a need for somebody to identify it and bring it out I think. I think it's helpful generally for patients to know that somebody is there and maybe that is what helps to keep stability, I don't know, but I think it's an essential thing. Whether it's used properly here is a different matter because I keep being told that if you were to see every patient coming here with a breast lump, benign or malignant, you couldn't cope, I just wouldn't be able to cope with them all. But I don't know, I'm not being given the chance really to decide on that. So I do or I have developed the more practical aspects, for example fitting of breast prosthesis and compression bandaging for lymphoedema. I tend to like these more practical things but they're still part in a parcel of patient care. But to go and see women with gross arms and have medical staff, GPs particularly saying no dear there's nothing we can do about that. I'm trying to let the GPs know at this juncture that I'm here and what I can help to do for them.

IK: So you see your counselling role very much as a practical sort of help?

NC2: Yes, that's why I said at the beginning it's emotional and practical care I give, really. But I tend to have a low opinion of myself on counselling. I never use this word counselling and that's why I didn't in the introduction either because, but it depends what counselling is. To me it's helping. My definition of it is helping so I just help by all the grey areas of giving information or supplementing information and just providing whatever the woman really needs. Whether it's information or whatever. I just feel I can help in anyway I can.

IK: So you really don't call yourself a counsellor?

NC2: No.

IK: Just a breast care nurse?

NC2: Well I haven't got an actual qualification in counselling and as LF has said unless you have you should not call yourself a counsellor. In some of her writings she's actually been quite critical of nurses like myself calling themselves counsellors when they have no right to. Maybe that's influenced me a lot in my decision of not calling myself a counsellor but no, from the start I was a breast care nurse and after I did the course in London I put a specialist onto it because I had done a specialised course and achieved that but no. Maybe I've got a low opinion of myself, I don't know.

IK: So maybe really you could tell me what you think about the training in oncology counselling and maybe the efficacy of counselling?

NC2: Oh, the training is really, the training I got is part of the course, was helpful.

IK: The Marsden course?

NC2: Aha, it was helpful but it wasn't, it was just two experienced breast care nurses encouraging role play, really, is how we were taught but I'm sure there's a lot more, there is a lot more to counselling and unless one took on board to do that extensive course as is advertised in Glasgow or somewhere like that then I think, I mean that would be very, very worthwhile. I think it is probably an essential thing to do. Maybe my successor might have that qualification.

IK: So basically what you **are** trying to say is that such courses are needed and nurses who are going to be employed as specialist counsellors may need a lot of training?

NC2: I'm going along with what medical staff have said. In other words we shouldn't dabble where we don't know but I still feel we contribute a fair bit as we are without this specialist thing but to be correct in every sense I think we should have a bit more of the official counselling instruction given to us. Really we should pursue that. I don't know. It's just so that you feel properly - I can't get the right words - 'geared up' for the role that you're trying to do. I mean I've done the course, the actual breast care nursing course but I haven't done other than the local counselling course which was helpful as well. I haven't got anything else that perhaps the LF of this world would say that we should have to be able to do the job in its entirety. But there's nothing wrong with common-sense and years of experience as you said yourself before, that everybody feels with the years of nursing experience behind them that you can cope adequately to help women but whether it needs this extra other certificate. I just would probably feel more confident myself if I had, it but whether I would do the job any better is another matter.

IK: Do you have any sort of idea of the efficacy of counselling or so called specialist breast care?

NC2: No.

IK: I mean is it really helping women, this service, helping women to be psychologically better off?

NC2: I think it must do. They'll probably, I'm talking of this service here, they probably don't know, they **don't** know my feelings about counselling so they think they're being counselled when I don't use that expression. But I think there are benefits because you're taking a woman aside on a one to one basis, away from the hustle and bustle of the ward and just coping with her emotions really and this traumatic experience that she's going through. It's **bound** to help. It certainly won't hinder it, I mean I don't think it can do anything but good. But I suppose the other side of it is you're getting down to ask really deep questions about herself and how she thinks she's going to cope with this and how will it affect her, what does she think of her own appearance and how her breasts are important to her and all this sort of very personal types of questions, you can go into that depth. Then there are occasional women who might think this is an invasion of privacy or something, I mean they haven't actually said to me 'enough of this, this isn't appropriate, it's not relevant' but sometimes I wonder just, I mean I adjust the interview according to the type of person in a sense because I wouldn't ask the same questions of an 85 year old as I would with a 35 year old.

I think it is effective and essential for most of the women but they look on it, they talk, they refer to me as a 'counsellor' strangely enough.

IK: They do?

NC2 - Yes. So they look on it as counselling and they refer to their friends when they go home 'Oh I had the nurse counsellor in to see me and she's coming to see me' or something like that but they don't get that word from me. But it seems to be effective.

IK: Do you have psychologists or psychiatrists working in collaboration with you? You refer women that you are very concerned about or how does it work?

NC2: Right, good question. This was something on the course that we were advised to have, both from our point of view and for the patients benefit as well. I came back and discussed this aspect with our surgeons here and they very much have said that the availability is here, that we have two psychologists working in the hospital, I think they're both part-time here, they're only here for certain sessions but the medical staff wish to be, to make the referral, that is very clear. Has been made very clear, that they wish to do the referring. In other words, if I'm not happy about a patient emotionally, psychologically, call it what you like, then I have to refer, mention that to the medical staff responsible for that patient and they will deal with it if they think it's appropriate. They would see the woman and then... Now that happened only last week. There is a lady who has had a bilateral mastectomy very recently and after the first mastectomy which was 3 years ago, I wasn't involved with this lady, it was pre my appointment. Anyway that lady went completely off the rails. She needed a psychiatrist help from Edinburgh followed by a psychologists help locally here and then she began to improve and pick up the threads. Sadly three years later she has sustained another breast cancer and this time I'm really not sure how she's coping. On the surface OK, but deep down I feel that she's not as good as she should be. So on that basis I went to speak to the surgeon looking after her only last Friday. He was seeing her this Friday and he has said to me that he can see from what I've said to him that he's going to have to refer her for specialist help again. But they want to do it, the doctors want to do it, I haven't got that authority. That has been made very clear to me from the early days.

IK: How do you feel about it?

NC2: Perhaps I'm not a fighter. I'm one of the old school, very dominated. In fact, you know, very kind of subservient to the doctors and it doesn't alter me very much because that's my type of training I've had and therefore I just accept it. I have to. Because I don't have the back up of the Nursing Administrators here who are prepared to argue in any way for me really. I often wonder - I'm talking locally obviously - that I don't really know what the medical staff's opinion, not opinion but I don't know what their expectations are of this role of mine pertaining to this hospital. I know what I want to achieve but unfortunately my hands are tied in many ways and the specialist in Edinburgh doesn't want me 'dabbling' either. So really with this, with knowing all this background I

feel, I suppose a wee bit inhibited as to what I can do off my own bat. However I do my best and that's all one can do really. But obviously if somebody is finding it hard to cope then the respective consultant wants to know from me, I haven't got the authority to refer to anybody else.

IK: But you have cases where you came to the consultant and said well this lady I'm concerned about?

NC2: Yes, but where do you... It's hard sometimes to know what's just a normal reaction, you know, that people do have their ups and downs and their goods days, we all know that, they have good days and bad days but I've had nobody that's, well yes I have, there has been one lady in particular who found she couldn't cope and her GP referred her to a psychiatric Community Nurse and she still had me so between the two of us. She felt, the nurse felt I had the expertise about the breast cancer aspect and she had the expertise about the psychological aspect and together we helped this lady through it. So I could via the GP get the help of the psychiatric community nurses so I could do it that way. But it's not getting true psychologist help. But we were also, in London, advised to liaise with a psychologist locally for our support. I did that at the beginning, came back and sort of got to know the psychologist a bit better along with the stoma care nurse who went with me but she didn't really feel that there was a need to see her regularly. That was only one of the two that I went to see.

So really there isn't a lot of support for us. As you saw I have a shared office, the two stoma nurses are there and sometimes we speak about patients that we have got problems with and I suppose that's the only way we can...

IK: But you meet with the Scottish network?

NC2: Oh yes.

IK: That's important.

NC2: We meet every so often.

APPENDIX 8

Letter Following the Transcript of Interview

Ilana Kadmon
Nursing Research Unit
Dept. of Nursing Studies
University of Edinburgh
12 Buccleuch Place
Edinburgh
Tel: (031) 650-8442

1991

Dear

It is a while since our meeting and I would like first of all to thank you very much for having me over and sharing some of your thoughts and experiences. This has provided valuable contribution for my study.

Enclosed find a transcription of the interview. I would be glad if you would comment on points I might have misunderstood or any unclear facts. Perhaps there is something you would like to add? If you have the time, and feel like it, it would be much appreciated if you could send the transcription back with your comments.

In the meantime all the very best,

Sincerely,

APPENDIX 9

The Response of the Women to the Transcript of the Interview

Each of the women participating in the research kindly commented on the transcript of our conversation. Here are some examples of notes which they attached to their comments.

RUTH

Dear Ilana,

I am sorry for the delay in my reply but it has been a devastating week with two friends having parents dying, then my youngest daughter and her husband springing divorce on us!

I've made minor alterations in the transcript.

Apart from that the only comment is that in talking to you I ran the two days at [the hospital] prior to the operation into one. The first time going there was for the cytology and the surgeon gave the result which confirmed the [screening centre] diagnosis. We returned for the staging day which was when we were there so long and given the provisional decision as to treatment. The final decisions being given to us when we returned again the following morning after the surgeon and the radiologist had conferred.

I have thought more about counselling or even just information giving and think you both could and should get some earlier, such as at the [screening centre] stage. Although I only had the second mammogram there and not the cytology that is the stage I knew for certain that the news was bad and it had not just been a mistake in the first mammogram.

I still feel that I personally was lucky because I had so many friends that had "been there before" but in spite of the current high incidence the people that I was with in hospital hadn't had this benefit and would most certainly have appreciated something from nurses to replace what I had from friends.

All good wishes Ilana, I hope you get things going in Israel. If things are still not quite clear please contact me, and I hope you can read the writing.

Yours sincerely,

SOPHIE

Dear Ilana,

I've nothing really to add. I'm doing very well and the tumour this week is 1.6 c'm so I seem to be winning. Hope our meeting was a help to you in your studies and please feel free to contact me anytime.

Yours sincerely,

ANGELA

I return your transcription of the interview.

As you will see, I have made a few minor alterations. Apart from these it is a very fair and true interpretation of our discussion and I trust it will be helpful to your study.

Please do not hesitate to contact me in the future if you wish. I would be most happy to hear from you again.

Yours sincerely,

LUCY

Dear Ilana,

I have changed some sentences and find everything alright.

I am keeping fine,

Yours,

ROSE

Dear Ilana,

Thanks for letting me see this. Have made a couple of amendments. I'm on my 1st week of Radium Therapy and keeping well,

Regards,

SANDRA

Thank you for sending me a copy of the transcript of the interview, which I hope I have been able to add a few details to, to help you.

I found it very interesting reading it over, and sincerely hope it will help you in your study. I hope also that you have been able to interview other women in the field (who were hopefully better at talking than me), who have also helped.

Thank you again for your time and patience with me - how I wish I had been a better interviewee! - maybe I was a bit nervous. Next time I shall speak up.

Sincerely,

LYNN

Dear Ilana,

I thought I would write to you rather than try to contact by phone.
I didn't half talk! Quite a manuscript! Of course I am happy to clarify and make comments where necessary. Time and my return to normal life, i.e. work, mean I see things a little less emotionally. So I think it is appropriate to be given the opportunity to read the transcript.

I wonder if rather than return it to you, would you like to come and eat - say around 5pm one evening? Any day would work out. If 5pm is too early, any time thereafter would be O.K. too.

In the meantime I hope your research is going well,

Best Wishes,

APPENDIX 10

List of Themes

The Decision-Making Experiences

The Woman and her Self-World

* Being Alone and Feeling Lonely
* The Burden of Making a Choice
* Personality and Age
* The Health Concept
* The Breast as a Symbol of Femininity
* 'Just Want it Away'

The Relationship with the Doctor

* The Doctor Knows Best
* The Right of Choice
* Wanting to be Helpful

The Importance of Support

* The Role of the Husband/Partner
* The Role of the Family/Children
* Social Support
* Women to Women Support

The Role of the Nurse Counsellor

* The Timing of Counselling
* Counselling as a Source of Explanation, Information and Advice
* Emotional Support
* Nursing and the Holistic Approach in Counselling
* Limitations of Nurse Counselling:
    'Having Been There'
    Too Busy - Not Enough Time
* Using the Word 'Counsellor'

APPENDIX 11

Letter of Invitation to the Group Meeting

Ilana Kadmon
Nursing Research Unit (3rd. Floor)
Dept. of Nursing Studies
12 Buccleuch Place
Edinburgh
Tel: (031) 650-8442

6th January 1992

Dear

I hope all is well and that you are doing fine. I would like to thank you at this stage for all your help and cooperation in my research.

You will remember that I was in touch with you last year, when I sent you a copy of the transcript of your interview. As a follow-up to the interviews, I thought it would be most helpful to get together the ten women I have talked with. This meeting will be informal.

The purpose of this meeting is to discuss the common themes and **not personal details** which have emerged from the interviews. I also want to check my general understanding of issues. I am planning to have the meeting on Monday, 10th February at 7.30pm, in my office address.

It would be a great help if you could come to this meeting. You are, however, under **no obligation** to do so. If this day or time is not suitable then we can perhaps make other arrangements.

Could you please return the attached slip to me, to my office address in the enclosed envelope.

I am greatly looking forward to seeing you.

Thank you once again,

Yours sincerely,

Name:

Please mark one option:

* I will attend the meeting on the 10th of February.

* I will **not** attend the meeting on the 10th of February.

* I would like to attend such a meeting, but a different time would be better for me. The more suitable day of the week for me is:

APPENDIX 12

Extracts from Transcription of the Group Meeting with the Women who were Individually Interviewed

This group meeting was transcribed phonetically, trying to keep to the local Scottish dialect. In the following appendix examples of extracts from a discussion of two issues are provided.

The Topic of Being Alone and Loneliness

IK - One of the things that occurred quite a lot, you know, it doesn't say anything specific so you might say I didn't talk about it but this is something that did come up and it is really the feeling of alone. How much one does feel alone during this decision making experience. At the end of the day it is us who have to decide and it is us alone and no-one can help us and that's it. Now just before we open that for a wee discussion, there's just something I've read very nice that I would like to tell you. Actually, an Israeli psychologist that wrote a very interesting book with an oncologist in London called Maurice Slevin, they wrote a book together and they call it "Challenging Cancer from Chaos to Control", really how people control the illness. Now one of the things they really says very nicely is this: The difference one has to put in life between being alone and between loneliness. Now these are two completely different things. Now being alone is what is called in very philosophical English, it is an existential phenomenon, it's a basic thing of life. I'm Ilana I'm me that's me and I am in life alone and my world is like a circle and I'm the centre of of that circle of my world and that's it. No-one can be the centre of that circle. No circle has two centres and I'm the centre of my circle, right? So this is being alone and there's nothing to do about it, we can only acknowledge it, live with it, we can either fight it or we can live in peace with it but that's it - its there. Now the topic of loneliness is something completely different. Loneliness is really not being in much contact with the world and is not having much support, this is what we all know is quite a frustrating sort of feeling but its very important not to confuse the two. Now many people get very frustrated by trying to put someone else into their life - into the centre of their circle in order to not be alone and that is something that cannot happen. So I think that if one really acknowledged this difference and understand it it makes some things for us much easier to maybe cope with.

- I am very impressed.

- So am I.

- Its a fair comment and I think that the existential phenomena in explaining being alone is one that people do not think about. I mean to be alone, you don't necessarily have to feel lonely because being alone is not really loneliness. I mean how many of you live on your own and a lot of people that still live on their own totally independent even that they don't necessarily feel it. Its an interesting thought to think more about, especially in a relationship.

- Exactly.

- I have two experiences since I spoke to you Ilana, I have fallen out with a very dear friend and I'll never speak to her again. Never, ever, ever.

IK - You feel you've been let down?

- Yes, very badly let down and also with my neighbour. We've been neighbours for six and a half years and we were the best of friends and I'm not a depressive type I never let this ever get me down and Margaret let me down and Margaret could vouch for that, right? But at the end of the day over two silly things that happened I thought "I wish you could have been and seen what I've seen in the last year and four months" and I felt a bit lonely then because I thought they are causing a disagreement with me. When I've been and seen and done it all and met people like this ye know. I've been a bit disillusioned by some people since I had breast cancer and I think if you have a disagreement with somebody it can make you feel quite lonely as opposed to being, I should say lonesome. Ye know.

- Well, I found that when I had this first I did feel alone not lonely, but alone. But as you spoke I made nae secret aboot it ever an I went roond and ah met people that hud this seven year ago and ah know somebody who had this thirty years ago. And it made quite a circle of friends that hud the same an they'd all bin success stories so ah found that boosted ma moral quite a lot.

- I'll take that one stage further actually, because I had quite a peculiar experience with a known person... I wouldn't say she was a friend of mine but she was a bit more of an acquaintance. We'd known each other and used to meet in the same places at the same time, kept in touch. I'd met one of her daughters through work and all that sort of thing you know, and one of our mutual friends rang me up one day and said 'Have you seen June?' I said 'No I haven't. I thought she was in Canada and he said 'well I met her just two or three days ago coming out of the shop with the girls', and I asked 'what was up?' and she said she'd just been out a long walk. She said 'uhuh' and she was quite OK and quite OK about that. Then she said she was very afraid and very concerned and that she has no idea what's its going to be like living with the trauma and would very much like to talk to somebody. 'I laughed like a drain and gave her your address'. 'Oh get one of your old friends to ring you up' which she

couldn't believe. I rang up and she's kept in touch with me ever since. I mean more closely than we could have done because any time she's going to have an appointment...

- So what you're trying to say there is that she found what the word I'm looking for, comfort you might say through you. Well you see, I got it through Margaret because we went in together for staging and we became friends and if we had something that was bothering us, rather than phone up a 'Reach for Recovery' group ah rang Margaret.

- You feel really lonely when you're first told and you don't know anything about that.

- That's right.

- If they said bring somebody with you for the results its always anticipating it. That's the hard bit, the women that come out of the room who are told on their own their emotions are... you either bring somebody with you or...

IK - I remember you telling me specifically, R. let me stop you.

- It was a bit more unusual experience. My notes got to the bottom of the pile and Mr D ah just waited and waited and waited and the houseman took notes and called... he just read and went straight into this cancer or you know some that's great I can't remember now that's weird and I started to cry and lost control of the situation. It was something I should have left and he couldn't cope with that and he left me and nobody came back so I was left in a room sobbing and crying and then I began to sort of you know get really, really, stressed and by the time Dr D and [the counsellor] came I was out of control and it didn't have to be like that. Didn't have to be like that at all. It was a... I don't know what the answer is to that you're having to go in you know your going to get the result so they should have somebody there to attend with you.

- Ah think they always like somebody to be with ye. They're always sort of saying...

- At that moment in time as you say you like somebody to be with you.

- They like somebody to be wi ye when ye get the result.

- For somebody that disnae huv anybody it was worse...

The Topic of 'Just Want it away' and the Idea of choice

IK - The next category is really the concept of the breast and its a bit sensitive to talk about but here we are, we can feel a bit free now. There are two things there. First, the breast is a symbol of femininity and body image and sexuality and what is connected to it like we all know and the second thing is really what is very widely expressed, its really the words "I just want it away" I think there's not one woman who hasn't said this phrase in some way or another. Now, I asked myself just wanted it away - 'want away the cancer?' 'want away the breast in order to be sure the cancer is away?' and this is something I would really like to discuss. Just want it away - you belive you have your breast taken off the cancer is gone you have peace of mind, you have talked about the peace of mind when the breast is taken away so this is just want it away - maybe we can...

- We were all waiting for you to say that (nods of yes).

IK - You all felt that when you have your breast taken off...?

- Well, its been done so long hasn't it? that's that what your... even though so much...

- Its not so noticeable isn't it... so to a woman... you can wear white blouses and sweaters so I think most people think that if you have this breast removed and hopefully all the cancer's gone, then you can take the breast of.

- Getting the cancer away is more important.

- Yes.

IK - But there again, when I ask the next question then hypothetically some of you would not choose to have a masectomy. I ask hypothetically lets say you have been given the choice whether you want to have a mastectomy or a lumpectomy done. There is sort of a mixed feeling isn't there still?

- Well, it depends on the size of the tumour doesn't it. In my case they said its 4.3 cm' or whatever. Anything over 4 is really too much for a lumpectomy. They said 'We could do a lumpectomy but we couldn't guarantee you wouldn't be in for a masectomy in a few months time'. So my attitude was if its over 4, just take the lot away - you know.

- I didn't get a choice. It was just a straight masectomy.

- We found that a high number of patients that were in for a masectomy had originally had a lumpectomy. Quite a high proportion.

- Even quite rapidly actually.

- Yes, some were in within a year from the lumpectomy.

- some within weeks.

- I kind of got the impression that Dr. M just thought 'We'll do a lumpectomy' because it was never really discussed cos it was small and so the decision wasn't there for me so I had that and then appeared a second tumour within six to eight weeks after chemotherapy so that was really kind of spread from my point of view.

IK - Now lets talk about the right of choice really. Again, that also came up and also some wanted to make the decision some were unhappy to make the decision on the other hand and expressed that the doctor knows best, what do we make of that?

- They give you a choice but they've already decided what you need themselves. But there's two different routes to that. In other words its threatening, after all they only get you involve when... and they ahve the expertise.

- They give you the choice when they've already gone through the ideas themselves.

- When they're really not sure...

- There are sort of two levels pro choice and no choice.

- Yes, that's right.

- I think also sometimes they are giving a woman a choice of lumpectomy or masectomy just so that the woman feels in a way that she chose to have the mastectomy. If she has decided it she may feel that it has not been landed on her, that it was not forced on her. I think that's only fair, you know.

- But then if in the medical appointment, ye know how they examine you, bring it up on a computer and everything, and it gote tae be a mastectomy then ye huvnae got a choice that's it - there's nae choice.

- Having a mastectomy may be a choice. I think what your getting is having it presented to you in such a way that you don't feel you don't have a choice.

- Ah didnae get that choice as ah say.

- No, but you would have made the choice probably given the facts but you weren't given the choice. Now its your body and a lot of people feel that facts should be fully explained to you and then you should make the choice even though...

- Absolutely. So there is no real choice then. That's an argument.

- Well, I think it has to be...

- It all depends on the individual case, ah suppose.

- We're all individuals and what suits you and involves you, just you, you are the only one.

APPENDIX 13

Information Sheet for Patients Undergoing Treatment for Breast Cancer

The treatment of breast cancer may include not only treatment to the breast but general treatment, which is designed to protect you against recurrence of cancer.

Treatment of the breast may be by surgery, by radiation, or by both. It does not necessarily include mastectomy. General treatment can be carried out in two ways. The first is to reduce the levels of hormones circulating in your body, as these hormones may stimulate the cancer cells to grow. Reduction of hormone levels is achieved either by removal of the ovaries or by giving drugs which block the production of hormones. The second kind of general treatment is to give drugs which destroy cancer cells (this is called chemotherapy). It is very important that we determine which combination of these various types of treatment are the most satisfactory in all aspects. The best way of doing this is to use different treatments in different women with similar disease.

None of the treatments we practice are in any way experimental. All are normally in use in this hospital and in many parts of the world. The studies which we are carrying out are part of a large project which is being conducted in all Scottish University Medical Centres.

The particular study in which you are now being asked to participate is one which the cancer will be removed from your breast, as well as a few lymph nodes from the armpit. The breast will <u>not</u> be removed. The information from this operation will enable us to plan your future care. If it is decided that you should receive one or more of these further treatments (radiation, or hormone treatment, or chemotherapy), they will be selected for you by drawing options randomly. This is a well-established method for comparing treatments.

You can be assured that, should any particular type of treatment be regarded as best for you, you will receive it. In this event, you would not be included in this study.

Finally, if you decide that you would prefer not to take part in this or any other studies, the standard of care which you will receive will not be affected in any way. Whatever the circumstances, you will be treated by the best methods available.